

MASTER'S THESIS

Using HIT to support informal caregivers of cancer patients at home

A needs assessment

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Abstract

Introduction: This research investigated the requirements of an HIT solution that is usable and useful to informal caregivers of cancer patients on home palliative care.

Methodology: A needs assessment method was used with an exploratory and a confirmatory stage. Eight semi-structured interviews and two focus groups were used for data collection. Qualitative content analysis was used to analyse caregiver experiences with both inductive and deductive coding.

Results/Discussion: Expressed and unexpressed caregiver needs were extracted into four categories, *Implementation*, *Presentation*, *Information*, and *Practical Caregiving*, and used to create the application requirements. Five user personas were created based on caregiving intensity and the functional level of the patients, a method of tailoring the application content to the different personas was created, and a low-fidelity prototype of the application was designed.

Conclusion: The findings of this research can improve the preparedness and coping of informal caregivers of cancer patients on home palliative care.

Table of Contents

Abstract	iii
Table of Contents	iv
List of Tables	vii
List of Figures	viii
Acknowledgements	ix
Dedication	ix
CHAPTER I: Introduction	1
1.1 Background	1
1.2 Research Objectives	3
1.2.1 Research questions	3
1.3 Organization of Thesis	4
CHAPTER II: Literature Review	5
2.1 Literature Search Strategy	5
2.2 Operational Definitions	7
2.3 Caregiver Support	7
2.4 Caregiver Informational Needs	8
2.5 Using HIT to Deliver Support	10
2.6 Currently Available Educational Resources	11
2.6.1 Applications	11
2.6.2 Websites	12
2.6.3 Books	13
CHAPTER III: Methodology	14
3.1 Conceptual Framework	14
3.1.1 Participatory Medicine	14
	iv

3.1.2 User-centred design	15
3.1.3 User personas.....	16
3.2 Needs Assessment Method	17
3.3 Data Collection.....	19
3.3.1 Data Sources	19
3.3.2 Recruitment	21
3.3.3 Face-to-face and telephone interviews	22
3.3.4 Focus groups.....	23
3.4 Data Analysis	24
3.5 Quality of Analysis	25
CHAPTER IV: Results	27
4.1 Stage I	27
4.1.1 Caregiver needs	27
4.1.2 Table of requirements.....	32
4.1.3 Personas	32
4.1.4 Application mock-up.....	36
4.2 Stage II	37
4.2.1 Caregiver needs	38
4.2.2 Application requirements	39
4.2.3 Application prototype.....	62
CHAPTER V: Discussion	64
5.1 Informal Caregiver Needs	64
5.2 Application Requirements.....	67
5.3 User Personas	68
5.4 Recommendations	69

5.5 Limitations of the Study.....	71
5.6 Contributions to Knowledge	72
5.7 Future Research.....	72
CHAPTER VI: Conclusion	74
REFERENCES	75
Appendix A: Key Concepts from Literature	82
Appendix B: Study Design	85
Appendix C: Recruitment Material	86
Appendix D: Consent Forms	94
Appendix E: Study Protocols	96
Appendix F: User Personas	103
Appendix G: Coding Schemes	108
Appendix H: Low Fidelity Application Prototype	111
H2: Low Fidelity Application Prototype Final Version.....	115
Appendix I: Initial Tables of Requirements	119
Appendix J: Caregiver Needs with Relevant Quotes	129

List of Tables

- Table 1.1:** Caregiver Support
- Table 1.2:** Caregiver Informational Needs
- Table 1.3:** Using HIT to Deliver Support
- Table 2:** Participant Selection Criteria
- Table 3:** User Persona Combination
- Table 4.1:** Availability of Resources
- Table 4.2:** Functional Decline
- Table 4.3:** Disease Information
- Table 4.4:** Disease Trajectory
- Table 4.5:** Treatment Options
- Table 4.6:** Contextual Considerations
- Table 4.7:** Process of Dying
- Table 5.1:** Emergency Measures
- Table 5.2:** Equipment
- Table 5.3:** Medication Management
- Table 5.4:** Mobility
- Table 5.5:** Nutrition
- Table 5.6:** Pain
- Table 5.7:** Personal Hygiene and Elimination
- Table 5.8:** Physical Symptoms and Comfort
- Table 6:** Presentation
- Table 7.1:** Needs of Less-Intense Low-Need Caregiver Persona
- Table 7.2:** Needs of Medium-Intensity Low-Need Caregiver Persona
- Table 7.3:** Needs of Medium-Intensity Intermediate-Need Caregiver Persona
- Table 7.4:** Needs of Medium-Intensity High-Need Caregiver Persona
- Table 7.5:** Needs of High-Intensity Caregiver Persona
- Table 8.1:** Quality of Care Literature
- Table 8.2:** Educational Needs Literature
- Table 8.3:** User-Friendliness Literature
- Table 9:** Caregiver Needs with Relevant Quotes

List of Figures

Figure 1: Literature Search Model

Figure 2: Study Design

Figure 3: Map of Study Results Chapter

Figure 4: Introductory Menus of Application Prototype Interface

Figure 5: Pain and Medication Screens of Application Prototype Interface

Figure 6: Informal Caregiver Needs

Figure 7: Adjusted Introductory Menu of the Info Screen

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Dedication

I would like to dedicate my thesis to my mother, father, sister and brother. I know you had a hard time dealing with the long-distance arrangement but you still managed to continue providing me with the same unconditional love and support you have always given me. You are my favourite people in the world and I love you from the bottom of my heart.

CHAPTER I: Introduction

This chapter provides an overview of this study's background, objectives, and research questions. It will then describe the overall organization of this thesis.

1.1 Background

Informal caregivers play an increasingly involved role in today's health care system. Although they are often called "family caregivers," the term informal caregivers can describe friends, partners, neighbours, or anyone who provides or manages the care of an ill or disabled person without direct compensation (Levine, Halper, Peist, & Gould, 2010). Approximately 2.7 million Canadians currently provide care for family members or friends in an unpaid capacity, including 80% of the care for chronically ill people, estimated at 83.7 billion CAD (Lum, et al., 2011).

While their role is considered "informal" by provincial health care systems, caregiving responsibilities are costly and stressful to the caregivers, often taking time away from jobs, social activities, and personal relationships (Bevans & Sternberg, 2012). With the nursing shortage that most health care systems are currently facing, which has been deemed a "global crisis" (Oulton, 2006), more demanding tasks are increasingly being shifted to informal caregivers, the majority of whom have no formal health care training (Northouse, Katapodi, Song, Zhang, & Mood, 2010).

Caregiver burden is a complex phenomenon, ruled by multiple competing priorities, concurrent taxing events, and exposure to prolonged, unrelenting stress. Informal caregivers of cancer patients experience high levels of distress that could sometimes even exceed those of the patients, with adult daughters reporting the highest levels (Bevans & Sternberg, 2012). Furthermore, a decreased caregiver quality of life is related to worsening physical and emotional well-being of cancer patients (Wadhwa, et al., 2013). Primary stressors that contribute to caregiver burden include dealing with patient symptoms and personal care needs. This is compounded with a perception of a lack of adequate support from the formal health care delivery system (Brazil, Bainbridge, & Rodriguez, 2010), as

family caregivers report being insufficiently prepared to perform health care activities and manage home-care technologies (Wolff, et al., 2010).

A large percentage of terminally ill cancer patients in Ontario receive home care from informal caregivers with no prior experience providing health care or supportive care (Quality Hospice Palliative Care Coalition of Ontario, 2010). Further compounding this inexperience is the “taboo” nature of palliative care and the process of dying, which generates a lot of misinformation (Wong, et al., 2002). As such, informal caregivers of patients with advanced cancer receiving palliative care at home is a population with complicated care needs that need addressing.

While there is a growing body of research on informal caregivers, much of it has focused on treating caregiver stress or bereavement through psychological support interventions and alleviating caregiver burden by streamlining their tasks and providing them with more resources (Northouse et al., 2010). Bevan and Pecchioni (2008) found that the health education of informal caregivers has gone largely under-researched, despite evidence that stresses the importance of caregiver health literacy for good patient outcomes. Moreover, the need for caregiver education on health and health management issues has been emphasized as an important component of high quality participatory care that should be integrated throughout the continuum of care (Levine et al., 2010). Fulfilling the informational needs of informal caregivers not only empowers them but also has the potential to improve their coping mechanisms and quality of life and subsequently to decrease the caregiver burden (Wong, et al., 2002).

Literature has described the benefits of integrating caregiver support and education into the health care system, but research on the optimal ways to provide that support is still ongoing. The Internet was found to have great potential for delivering information to informal caregivers (Kernisan, Sudore, & Knight, 2010), especially since the majority of caregivers have a tangible interest in using it to learn more about their care roles (Zulman, Piette, Jenchura, Asch, & Rosland, 2013). However, the quality, suitability, and trustworthiness of the information currently available online has been called into question (Kernisan et al.,

2010). Additionally, only a few studies concerning informal caregivers of advanced cancer patients have been conducted in a home setting (Cui, Song, Zhou, Meng, & Zhao, 2014).

Research is still needed in order to determine the types of information required, the way in which it should be presented, and the most effective ways Health Information Technology (HIT) can be used to deliver it. Most importantly, HIT solutions must be tailored to the specific needs of informal caregivers, instead of being developed from a macro perspective to meet the needs of all caregivers. One way of guiding system design to reflect the true needs of users is by employing User-Centred Design approaches such as user profiles and personas, which can guide a developer unfamiliar with end-users to effectively tailor the design to them by considering their goals, desires, abilities, and limitations instead of relying on dry demographic information and stereotypical assumptions (LeRouge, Ma, Sneha, & Tolle, 2013).

1.2 Research Objectives

In view of the literature discussed above, this study aimed to qualitatively investigate what features should be present in HIT applications meant to provide family caregivers of palliative care oncology patients with support and information. It also drew upon User-Centred Design and user personas to determine the best way this information might be presented so that the product could be both useful and usable.

1.2.1 Research questions

Research questions were:

- What are the information needs of informal caregivers of terminally ill cancer patients receiving home palliative care in order to provide safe and effective care?
- How can we convert these information needs into system requirements for a Health Information Technology application designed to support informal caregivers of terminally ill cancer patients receiving home palliative care in a home or community environment?
- How can we tailor these requirements to different informal caregivers by developing user personas?

1.3 Organization of Thesis

This thesis contains six chapters, the first of which was the introduction. The second chapter will discuss the current literature and existing gaps in the areas of caregiver support for the study's population, and provide operational definitions for the concepts used. The third chapter of this thesis will present this study's methodology, including the conceptual framework, the research methods used, participant recruitment, data collection methods, and the methods of analysis.

The fourth chapter will present the results of each of the two stages of the study, including user personas, caregiver needs, and application requirements. The fifth chapter will discuss the findings of the study as they relate to the research questions, provide recommendations for practice and future research, and mention the limitations of the study. The sixth and final chapter will provide concluding remarks.

CHAPTER II: Literature Review

This chapter will discuss the current literature and existing gaps in the areas of caregiver support for the study's population, provide operational definitions for the concepts used, and describe the conceptual framework of the study.

2.1 Literature Search Strategy

The University of Ottawa's online libraries were used for literature search. Databases used included Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations and Ovid MEDLINE(R). One search looked for articles discussing informational needs in the title or abstract, combining keywords like "health information," "information exchange," "care information," "information need," "need for information," "support information," "resource information," and "information-seeking" with the Boolean OR operator. This was combined with a second search looking for articles focused around the subject "caregivers", using a Boolean AND operator.

This search was initially done in May 2014 and repeated in May 2015, then September 2015. A list of 215 articles was retrieved and then narrowed down by removing duplicates, non-English articles, articles published more than 15 years ago, and non-research articles. The list was further reduced by removing clearly irrelevant articles based on their titles. In total, 107 articles comprised this research's literature review. Furthermore, the reference lists of retrieved articles were reviewed and a large number of cited articles were added to the list.

The literature search mined the health care fields closest to the subject material of the study. Previous searches that included the word "cancer" retrieved too many unrelated articles that focused on things like new treatment efficacy, therefore the search strategy did not use that word or any related terms. Due to the intricate nature of oncology protocols, which can involve surgical interventions, radiation, and the administration of highly toxic and controlled chemotherapeutic medications, family caregivers often lack qualifications and the knowledge to participate in the curative side of cancer treatment, and are instead highly involved in the supportive aspect of care. Therefore, searching palliative care

literature was found to be more likely to render articles discussing informal caregiver needs than a similar search in cancer literature. Moreover, since cancer patients account for over 80% of home palliative care recipients (Quality Hospice Palliative Care Coalition of Ontario, 2010), the literature search was expected to contain enough cancer-related articles.

The abstract of each paper in the list was then read, and articles were selected based on how closely related they were to the research topics and how likely they were to contain information that can be used to answer the research questions or help with the design of the study or the analysis of the data to be collected. The article selection process and the literature search strategy were both guided by the conceptual framework, which will be discussed in section 3.1.

Information from each article in this paper's literature review was extracted into a literature table, and then the information was synthesised into sections that emerged organically, dealing with caregiver support, using HIT to deliver this support, and the informational needs of caregivers. A section was also added where currently available educational resources are briefly reviewed and critiqued. Figure 1 provides a model of these subjects as they intersect each other in this study.

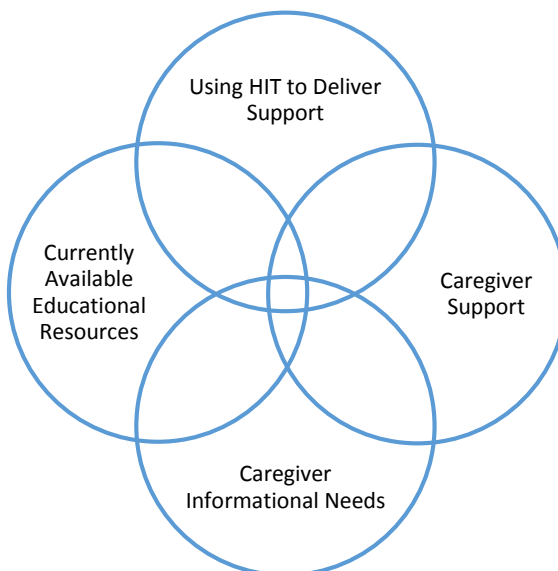


Figure 1: Literature Search Model

2.2 Operational Definitions

This section will define the major concepts used in this thesis.

- Informal Caregivers: Individuals who provide care to an ill or disabled person in an informal and unpaid capacity. They may be members of the patient's immediate family, but may also be relatives, partners, friends, neighbours, or others (Levine et al., 2010). In some publications, they are referred to as "carers," "family caregivers," or "family carers."
- Palliative Care: A philosophy of care whose aim is to relieve suffering and improve the quality of living and dying. It can involve physical, psychological, social, spiritual, and practical issues (HPCO, 2011).
- Information Needs: What informal caregivers need to know in order to provide safe and effective care. These may include unexpressed visceral needs, consciously described needs, and formalized needs (Taylor, 1962). Needs can also be idiosyncratic, according to the unique circumstances of the caregiver, or normative and shared by most people involved in cancer care (Adams, Boulton, & Watson, 2009).
- Persona: A narrative, in textual or pictorial format, that describes a fictional but representative product user. It should specify the goals the user intends to achieve by using the product, and describe his/her environment, qualification, attitudes, and the tasks he/she needs to accomplish (LeRouge et al., 2013; Rogers, Sharp, & Preece, 2011, p. 360).
- Requirements: A "singular documented physical and functional need" that a certain product or process should be able to fulfill in order to accomplish its design goals (Jawale & Bhole, 2015).

2.3 Caregiver Support

Northouse, Katapodi, Schafenacker, and Weiss (2012) found a reciprocal and significant link between patient and caregiver emotional distress, and noted that evidence-based interventions for dealing with this problem are often not applied in practice. They

suggested seeking new ways to implement such interventions that are based on an initial assessment of the needs of family caregivers (Northouse, Katapodi, Schafenacker, & Weiss, 2012). Harrop, Byrne, and Nelson (2014) found that informal caregivers feel insecure in their role, and recommended focusing caregiver interventions on developing caregiver competence, preparedness, and confidence (Harrop, Byrne, & Nelson, 2014). Wolff et al. (2010) found that using a guided-care model, wherein community nurses who work with primary care physicians provide guidance and support to family caregivers, improved the quality of chronic illness care delivered at home. They recommended that interventions be made more broadly accessible using a range of available communication methods (Wolff, et al., 2010).

Northouse et al. (2010) performed a meta-analysis of 29 randomized clinical trials dealing with psychoeducational, skills training, and therapeutic counselling interventions aimed at caregivers. They found that although these interventions had small to medium effects, they were still of significant help to caregivers. The interventions studied reduced caregiver burden and improved self-efficacy, ability to cope, and quality of life. They recommended future research to assess using technology to deliver effective interventions to caregivers (Northouse et al., 2010).

Levine et al. (2010) suggested that family caregivers should be treated as important care partners in care transition planning. They recommended that research be conducted to explore caregiver training and support for medical tasks in order to achieve a fuller and policy-relevant understanding of their unmet needs. They also suggested integrating the teaching of different care skills throughout the continuum of care. They predicted that this educational approach could have a major influence on decreasing unnecessary and costly re-hospitalizations and improving overall patient outcomes (Levine et al., 2010).

2.4 Caregiver Informational Needs

Caregivers often desire assistance with interpreting symptoms, knowing what to expect from disease or treatment, and learning practical care skills (Kernisan et al., 2010).

Washington, Meadows, Elliott, and Koopman (2011) warned against a paternalistic

approach that excludes patients and caregivers from learning all details of the relevant illness. This includes information such as prognosis and what to expect at different stages of illness (Washington, Meadows, Elliott, & Koopman, 2011). Brazil et al. (2010) suggested a person-centred integrated care system that would properly meet the needs of patients and their informal caregivers.

Wackerbarth and Johnson (2002) followed a needs assessment approach to understand the information and support needs of informal caregivers of Alzheimer's patients. They found that caregivers considered information needs more significant than emotional support needs. Information concerning diagnosis and treatment, as well as health plan coverage, was deemed more important than the type of general facts typically dispensed. Moreover, caregivers had different information needs that were likely to change depending on experience. They recommended that future research be conducted to investigate tailoring interventions to the needs of different types of caregivers based on gender, geographic location, and different points on the caregiving trajectory.

Washington et al. (2011) found that informal caregivers share a pervasive need for up-to-date, practical, and accessible information. Common categories they uncovered include disease information, treatment options, and availability of different services. They further suggested providing information about different aspects of illness at a range of different levels of health literacy. Pain and fatigue management, as well as home palliative care resources, were identified as the areas in which most information is needed by caregivers and patients suffering from terminal cancer in Wong et al.'s 2002 paper. Individual teaching and short written materials were considered the preferable mode of education. Additionally, caregivers showed more interest in a wider variety of topics than patients did, and a third of them were willing to participate in educational events (Wong, et al., 2002). Cui et al. (2014) focused on practical information needs of caregivers of advanced cancer patients, such as disease information, pain and symptom management, home care services, and management of depression, weight loss, and appetite loss. They found that physical needs such as symptom control were valued most by informal caregivers.

2.5 Using HIT to Deliver Support

Northouse et al. (2010) identified the need for research that explores the effectiveness of using technology as a mode of delivering interventions to caregivers, while Washington et al. (2011) recommended optimizing information available online so that it becomes accurate, timely, straightforward, readable, and patient-centred. Kernisan et al. (2010) analyzed the type of health information sought by caregivers online and found that “health information,” “practical caregiving,” and “support” were the most searched for categories. They recommended that researchers and practitioners treat “e-caregivers” as a group separate and distinct from “e-patients” with different concerns and capabilities, and whose needs transcended the categories that current health education resources are used to tackling. New categories were suggested that included geriatric principles such as functional decline and cognitive impairment. They further recommended future research aimed at exploring the Internet’s potential for caregiver education and support.

The category “health care” is already one of the fastest growing groups of mobile applications for both iPhones and Android-powered devices, grossing more than 1.3 billion USD in 2012 alone (Transparency Market Research, 2013). A study by Zulman et al. (2013) found that more than a third of informal caregivers (34.5%) already use HIT applications such as websites and mobile applications in their care activities, that the likelihood of using technology increases exponentially with the intensity of caregiving, and that most informal caregivers had a significant interest in using such technology. Furthermore, more than 70% of caregivers who were not currently using technology reported an interest in HIT and an intent to use it in the future. Caregivers complained of unfamiliarity with relevant programs and websites, distrust of information available on the Internet, and software complexity (Zulman et al., 2013). Videoconferencing, websites, and mobile applications have been suggested as tools with the most potential for supporting patients and caregivers (Demiris, Oliver, & Wittenberg-Lyles, 2011).

A review of the key concepts found in the literature review is provided in Tables 1.1, 1.2., and 1.3 in Appendix A.

2.6 Currently Available Educational Resources

Since the goal of this research is to develop a new educational resource for informal caregivers, a brief search was made to assess educational and informational resources currently available to this study's population. Most of this material has not been yet reviewed in scientific publications, but were instead discovered during the course of the study, often recommended by participants or some of the professionals who helped with recruitment.

2.6.1 Applications

A web search yielded Aplaceformom.com and Caregivers.com as relevant websites with blogs that rated and recommended some useful applications. Both sites were about senior care, not cancer, and therefore focused on senior issues such as functional decline, dementia, and senior depression, but they were useful starting points in gauging opinions about caregiver applications in general.

Some of the applications discussed on those blogs were reference sources that provided information to caregivers, and others were organizational sources that helped them manage and document their patient's health care (Napoletan, 2013a), or helped multiple caregivers of the same patient split their tasks more efficiently (Napoletan, 2013b). The applications that were discussed favorably were simple and easy to navigate, with white backgrounds, colourful graphics, and minimal text on each screen. They also had optional extra features that caregivers could choose to use but didn't have to, such as a chance to store contact information and a web version (Anderson, 2015).

The iTunes store and Google Play Store were also searched, but all cancer-related applications were designed for patients or professionals, not informal caregivers. When searching for caregiver-specific applications it was found that many applications that contain "caregiver" or "carer" in their title were geared towards nurses and Personal Support Workers (formal caregivers) or limited to apps designed by caregiver advocacy groups to put out newsletters and receive donations.

The Symptom Management Guidelines mobile application provided by Cancer Care Ontario is an application geared towards health care professionals. It has a simple interface which lists the symptoms common to cancer patients and then provides a section that contains assessment tools and another that lists and briefly explains possible interventions. This application was widely recommended by the nursing focus group participants to family caregivers of cancer patients, but it is obviously not designed with caregivers in mind. Despite all instructions being addressed to health care workers, the application does use a simple language that would allow family caregivers to understand most of the interventions suggested. They would have a harder time with some of the assessment tools, though, since they are written in a more professional language and often require some training in nursing or medicine.

2.6.2 Websites

The Canadian Virtual Hospice website (virtualhospice.ca), established in 2001, aims to provide information and support about palliative care and end-of-life issues to patients, families, informal caregivers, health care professionals, and others. It is jointly funded by three not-for-profit health organizations and has a National Advisory Committee composed of palliative care experts from all over Canada (Canadian Virtual Hospice, 2015).

The website, available in English and French, is split into three categories: “Topics,” “Support,” and “For Professionals.” “Topics” contains different articles about educational subjects such as symptoms, palliative care, spiritual health, caregiving, and financial assistance available in different provinces; this content is reviewed periodically and kept up to date. Furthermore, the use of reputable sources such as the World Health Organization and the professional associations that fund the site gives this information more credibility (Parry, 2013). “Support” is the part of the website where users can ask questions, review questions which have already been answered, or enter a discussion forum and share their stories. Finally, the “For Professionals” section offers advice and tools for health care professionals who need to learn more about palliative care practice, and advertises different courses and resources available for professionals and volunteers.

The design of the Canadian Virtual Hospice website is such that the main information is centered in the user's field of vision while quick-access links is on the right along with the twitter feed for @VirtualHospice. This website is widely considered to be a comprehensive and reliable resource for information on palliative care, as well as death and dying (Parry, 2013), but none of the participants in this study's interviews or focus groups were aware of its existence. Furthermore, due to the wideness of its audience, its design is not optimized for caregivers and it could be a bit difficult to find some topics. However, this website would be a very good resource for caregivers who desire to read further about their topics of choice, since it contains in-depth articles that are written in a clear language.

2.6.3 Books

The book entitled *A Caregiver's Guide*, developed and published by The Military and Hospitaller Order of St Lazarus of Jerusalem and the Canadian Hospice Palliative Care association, was cited by several interview and focus group participants as a good source for caregiver information, and was also recommended by some of the health care professionals and administrators who assisted with participant recruitment. This book was published in 2004 and focuses on end-of-life care, and provides brief yet comprehensive instruction on practical aspects of caring for palliative family members in a holistic way. It also touches on issues related to the caregivers' wellbeing and welfare, and refers them to further resources that may interest them, including financial and legal resources (Macmillan, Peden, Hopkinson, & Hycha, 2014).

This book, however, is concerned with all end-of-life and palliative issues, not those specific to cancer; thus it is focused very narrowly on the practical aspects of palliative care and contains little to no explanation of the original illnesses that would lead the patient to become a palliative care recipient. What probably makes this book so well-regarded is its use of simple non-medical words and clear illustrations, which should be emulated by all materials directed at the informal caregiver population.

CHAPTER III: Methodology

The literature review in Chapter II revealed the need for research that improves the understanding of different types of informal caregivers and the variation between their educational needs. It also highlighted the potential HIT has for addressing these needs. Chapter III describes the methodology of the study, including the conceptual framework, the research methods used, participant recruitment, data collection methods, and the methods of analysis.

3.1 Conceptual Framework

This study was situated at the intersection of the fields of health education, caregiver support, cancer care, palliative care, and home care. The conceptual framework guided the selection of the study's reference literature and its research design. It more importantly guided the creation of the deductive coding scheme that was the foundation for the entire research analysis. It also drew inspiration from two principles currently prevalent in the worlds of health care and interaction design: participatory medicine and user-centred design (UCD). Both of these concepts reflect new trends in which the focus is on the "clients," or persons meant to the recipients, and less on the providers of a certain product or service.

3.1.1 Participatory Medicine

Greater involvement of patients and their informal caregivers in the process of health care and health decision making has been necessitated by an increased prevalence of chronic illness in the last few decades, combined with people living longer with chronic illnesses. Participatory Medicine involves a redesign of the provider-patient relationship, in which patients and family caregivers are active and informed participants in the care dynamic (van der Eijk, Nijhuis, Faber, & Bloem, 2013). Moreover, involving patients in their own treatment tends to generate more favourable outcomes and has the potential to improve the safety and quality of health care, while reducing costs and increasing accessibility (van der Eijk et al., 2013).

Participatory medicine has been encouraged and supported by the development of recent information and communication technologies, like the Internet and social networks, which provide unprecedented access to all sorts of information that once was rationed out by health care providers (van der Eijk et al., 2013). An area of future research is the best way to design technologies that maximize the benefits of information sharing in participatory medicine. Ozkaynak, et al. (2013) recommend conducting workflow analysis for HIT applications from the perspective of the patient instead of the clinician, in order to understand health care delivery systems is a more holistic and pragmatic way (Ozkaynak, et al., 2013).

This research took a participatory medicine approach by involving informal caregivers in the development process for an application meant to be used by them, so that their perspectives and workflows are the focus of the design efforts. It also ensured that said application supported collaboration and two-way communication between family caregivers and health care providers. The study sought to empower caregivers and increase their confidence and autonomy by providing the right information in the right way.

3.1.2 User-centred design

User-Centred Design is a design method wherein the needs, qualities, and limits of end-users influence the planning, design, and implementation of the product or service (UXPA, 2014). The importance of considering caregiver needs in determining the components of the application made UCD a suitable approach to use in this study, which tried to integrate these concepts as a way of informing system design for informal caregivers.

User-centred design is driven by three main principles developed by J. Gould and C. Lewis in 1985 (Rogers et al., 2011, pp. 326-30):

- Early focus on users and tasks: The goals and tasks of the users are considered the driving force of the product's development. Users are consulted and studied in each stage of the design process, and their characteristics, behaviour, and context of use are determined and designed for. Users are also included in testing and revisions of the product before making it available for use.

- Empirical measurement: Goals are identified and documented at the beginning of the project and are then used to evaluate its progress.
- Iterative design: Decisions and designs are revisited and re-evaluated based on user feedback.

The User Experience Professionals Association breaks the UCD process into four stages: analysis, design, implementation, and deployment (UXPA, 2014). This study focused on the analysis and design stages. This research also encompassed all phases of the model of user-centred design (ISO 13407) created by the International Organization for Standardization (ISO) (Pagliari, 2007), although it was more iterative in nature than the sequential circular model. This model's tasks were conducted thusly:

- Understand and specify context of use was the main objective behind creating the representative user personas. Using the personas for the rest of the analysis allowed the context of the end-users to be the focus of the research and ensure that their emergent needs were more relevant.
- Specify the user and organizational requirements and produce design solutions were the focus of the largest portion of this research, since the main goal was discovering user needs and translating them into design requirements.
- Evaluate design against requirements was the main reason for Stage II of the study's design, in which representative participants of the study population evaluated and commented on the design requirements discovered in Stage I.

3.1.3 User personas

User profiles and personas are methodological tools used extensively in user-centred design to develop products that meet the unique requirements of the projected end-users. In order to account for the diversity found within the informal caregiver population while still being able to focus on specific user characteristics, goals, and needs, user personas were used throughout the analysis and design phases to represent different groups of caregivers.

LeRouge et al. (2013) define user personas as “structured ways of typifying a group of users in text and pictorial formats.” They describe them as a novel way of looking at user

characteristics that goes past mere demographics and tries to capture the mental processes users employ, including their expectations, prior experiences with similar products, and projected behaviour (LeRouge et al., 2013, p. 3). A persona usually consists of a narrative that specifies the goals that a fictional but representative user has for using the product; it also describes their environment, qualification, attitudes, and the tasks they need to accomplish. Multiple personas are usually written for each product to represent different user groups (Rogers et al., 2011, p. 360).

During this research, I attempted to formulate personas that represent a diverse population of caregivers. Participant characteristics that emerged from the first interview stage were used to create the personas which were then the focus of the design efforts. The analysis and recommendations were tailored around these personas' environments, qualifications, attitudes, and the tasks they needed to accomplish.

3.2 Needs Assessment Method

In order to understand the information needs of informal caregivers, this study used the Needs Assessment design as described by Gustafson, Taylor, Thompson, and Chesney for assessing the needs of breast cancer patients and their families (Gustafson, Taylor, Thompson, & Chesney, 1993). Their research followed an approach based on Akao's (1990) division of customer needs into three categories:

- Take-It-for-Granted Needs, which are the minimum expectations of a service. In this study, these would be things like patient safety and equal access to treatment.
- Typical Wants, which are attributes that end-users watch for and assess. They are almost always related to the quality of a service that is already present, such as the clarity of the information presented.
- Attractive Needs, which are those that the end-user is usually completely unaware of having. The researcher can deduce these needs through an in-depth analysis of users' negative experiences. In this study, these would include specialized features such as interactivity.

Gustafson et al. (1993) insisted on understanding patients' experiences as a prerequisite to discovering their needs. They further stipulated that the highest level of understanding is reached when unexpressed needs are revealed and services that exceed the expectations of the customer are designed. My study attempted to learn about informal caregivers' experiences in order to uncover the requirements of an application that guarantees the Take-It-for-Granted Needs, meets the Typical Wants effectively, and is able to include some Attractive Needs. It achieved this by harnessing emerging mobile and communications technologies to describe the features that need to be present in HIT applications to suit the needs of informal caregivers of terminally ill cancer patients effectively.

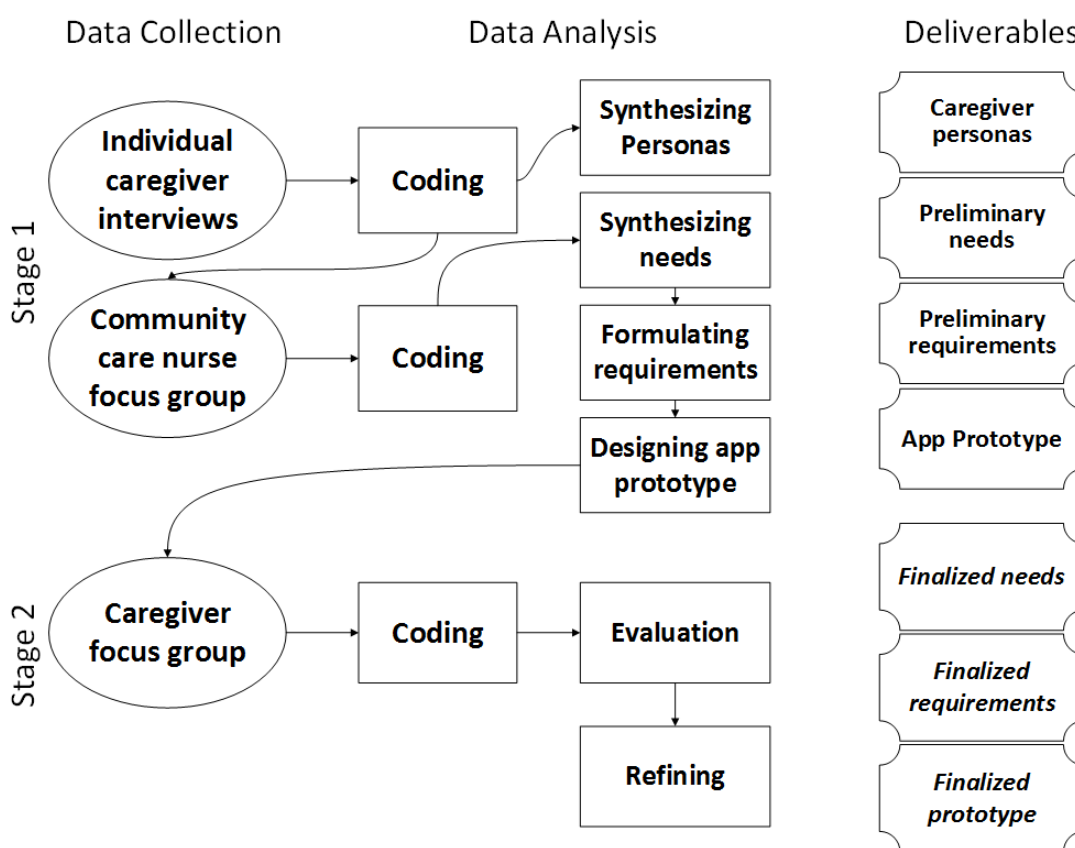


Figure 2: Study Design

This research had two stages of data collection, each followed by a round of data analysis. In the initial exploratory stage, open-ended in-depth interviews were conducted with a sample of participants. The output of this stage were five personas that represented

emergent subsets of the population, a preliminary list of requirements, and a few graphical mock-ups of a mobile app based on those preliminary results.

The second stage of data collection was a confirmatory phase in which a focus group was held with a smaller sample of participants to revise the recommendations that emerged from the first phase. This was followed by another round of data analysis where the focus group data were analysed for ways to improve and refine the recommendations. The second phase of data collection and data analysis was similar to Snodgrass and Coyne's widely used method of "hermeneutical circles," wherein an iterative process is used to implement a design, look for feedback, and then subsequently modify the initial design (Snodgrass & Coyne, 1997). The study design is illustrated in Figure 2, and a larger version is included in Appendix B.

3.3 Data Collection

3.3.1 Data Sources

Much of the available literature approaches the educational needs of family caregivers as determined by health care professionals, often from the perspective of the physicians, nurses, or allied health professionals who tend to the patient in a hospital environment and have trouble imagining the requirements of a home or community setting. Based on the principles of participatory and patient-centred medicine, which seeks to give patients and their family caregivers a more active role in care decisions and the management of patient care (van der Eijk et al., 2013), this study solicited informal caregiver needs from the informal caregivers themselves. Capturing additional data from community care nurses helped to identify further dimensions of caregiver needs, based on the community care nurse's unique perspective as someone with experience interacting with informal caregivers during their care process.

In selecting this study's participants, a purposeful sampling strategy as described by Creswell was used, as well as a criterion sampling of participants representative of the informal caregiver population (Creswell, 2013, p. 127). The intended population were adult family caregivers of advanced cancer patients receiving palliative care in a home setting.

The inclusion and exclusion criteria for study participants are summarized in Table 2 below.

Table 2: Participant Selection Criteria

	Inclusion Criteria	Exclusion Criteria
Informal Caregiver sample	<ul style="list-style-type: none"> • Over 18 years of age • Currently taking care of, or has previously taken care of for a minimum period of 1 month, an adult family member suffering from terminal cancer in a home setting in Ontario • Fluent in English 	<ul style="list-style-type: none"> • Being a caregiver in a hospital setting • Having previously received training or education in nursing or medicine unrelated to their caregiving role, such as physicians and nurses. • For Focus Group: Being part of the interviews will result in exclusion from participation in the focus group
Community Nurse sample	<ul style="list-style-type: none"> • Over 18 years of age • NP, RN, or RPN • Has at least 1 year of experience in Community/Home Care nursing • Fluent in English 	<ul style="list-style-type: none"> • Practices primarily pediatric nursing

A community setting was chosen for this research since it is in this situation that informal caregivers find the least support from the formal health care system. While family caregivers in hospitals are directly supported by health care providers, and rarely required to participate in providing direct care, in home-based settings they find themselves serving as the patient’s primary caregiver responsible for administering the most of the medical care. Senior residences were considered home settings as long as the residence staff provided only a basic level of clinical care, such as subcutaneous medication administration and sporadic vital signs measurement. In those cases, the family caregiver would have to be the person responsible for the daily care of the patient, including companionship, monitoring, administering feedings or oral medications, and substituting for lost functions. People taking care of cancer patients who were receiving curative

treatments such as chemotherapy or radiation were permitted to participate, as long as the patients were receiving palliative care as well. Moreover, it was important for the participants not to have attained any education in medicine or health care on a professional level, as that would not be properly representative of informal caregivers, the vast majority of whom have no previous preparation for providing care before being placed in a caregiving role (Northouse et al., 2010).

The study also sought information from community care nurses who had experience caring for palliative care oncology patients and providing teaching to their informal caregivers, and who could provide a more critical perspective based both on their education as well as their experience with teaching and supporting caregivers in a home environment. To maximize the amount of information that could be obtained from this participant group while keeping the sample size to a minimum, a focus group was conducted instead of separate interviews.

3.3.2 Recruitment

The Bruyère Continuing Care Research Ethics Board (REB) and the University of Ottawa Social Sciences and Humanities REB both provided approval for this study before participant recruitment commenced. Participants were recruited in several ways. Posters containing basic information about the study and eligibility criteria were placed in the family rooms of the Palliative Care Unit at Bruyère Continuing Care, and potential participants were encouraged to contact the research team. A different poster was used for each of the two stages of data collection, targeting informal caregivers for individual interviews and then for the focus group.

The Champlain Community Care Access Centre (CCAC) also assisted with participant recruitment. Nursing agencies involved with the CCAC were given a summary of the study design as well as the inclusion and exclusion criteria of the participants. Eligible caregivers of patients receiving CCAC assistance, or of those who had received it in the recent past, were contacted by the agencies and asked if they would be interested in participating. The contact details of potential participants were forwarded to the research team. The

caregivers were contacted, their eligibility to participate in the study was double-checked, a brief description of the study was provided, and their verbal consent was obtained to mail or email the Letter for Participation, which contained more detailed information about the study. Additionally, one informal caregiver participant from each data collection phase was recruited through personal contacts, after thorough vetting ensured they fit the inclusion and exclusion criteria.

Participants who chose to be interviewed in person were scheduled for an interview at a location and time convenient to each individual participant. Their questions and concerns about the study were answered and they signed the consent forms before the interview was started. The consent form was sent with the Letter for Participation for those who chose to be interviewed via telephone. Letters sent via regular mail included a pre-addressed and pre-stamped return envelope for the signed consent form, while those who used email printed the consent form and then scanned and emailed back the signed copy. Once the signed consent form was available, participants were contacted to schedule the phone interview.

Informal caregivers were recruited similarly for the focus group, the only difference being that only those living in Ottawa were approached. The focus group was scheduled at a time convenient to participants and letters for participation were sent ahead of time.

Participants' study-related questions were answered and consent forms were signed immediately before the focus group session was started. Community care nurses were recruited for the focus group from the agencies affiliated with the CCAC. Interested nurses were forwarded the Letters for Participation and encouraged to contact the research team. The recruitment material and consent forms can be found in Appendices C and D respectively.

3.3.3 Face-to-face and telephone interviews

Out of 11 potential participants, interviews were conducted with eight informal caregivers. Three of the interviews were in person and five were conducted via telephone. Five of the participants were female and three were male; their ages ranged from 38 to 70 years, their

educational levels ranged from high school diplomas to graduate degrees, and all were either related or married to their patients. Only one of the participants maintained full-time employment while providing care, while the rest either took time off their jobs, were already retired, or were otherwise not a part of the labour force. Their level of comfort with computer technology ranged from being very comfortable with most tasks to being completely unfamiliar and averse to using it.

The interview was semi-structured and open-ended, and can be found in Appendix E1. It was divided into four sections:

- Section 1: Given at the beginning, these questions involved the collection of demographics and background information.
- Section 2: These questions investigated the caregiving experience itself and the different tasks and responsibilities that the caregivers had to perform.
- Section 3: These questions investigated the different methods by which caregivers obtained information to provide care.
- Section 4: These questions investigated the caregivers' experience with computer technology and their level of comfort using it.

Since the study used a Needs Assessment design, the questions were designed to capture the experiences of the participants and then use them to derive their unexpressed needs. Participants were encouraged to talk at length about any relevant aspect of their experience, and follow-up questions were asked to gain clarification and a better understanding of their points. The participants were also required to recall an anecdote in which they felt overwhelmed by their caregiving challenges and to describe the manner in which they dealt with the situation. The length of the interview greatly depended on the individual experience of each participant, and ranged from 19:41 minutes to 54:16 minutes.

3.3.4 Focus groups

The nursing focus group, conducted at the boardroom of one of the agencies affiliated with the Champlain CCAC, was composed of four agency nurses. All participants had

experience caring for palliative cancer patients in a home setting, despite one of them recently transitioning to a managerial role in the field and another occupying an administrative desk job for the past few years. Like the informal caregivers' interviews, the focus group protocol was also semi-structured and open-ended, and the participants discussed their experiences caring for palliative patients and dealing with their informal caregivers. The focus group was very collaborative in nature and the conversation was enriched by the participants adding to each other's ideas and sharing similar experiences. The protocol for this focus group can be found in Appendix E2.

The informal caregiver focus group was the final stage of data collection. It was composed of three informal caregiver participants. Prior to conducting this session, the data collected from the interviews and the nursing focus group were analyzed and the deliverables from the first stage of the study were prepared, including the list of requirements for the application and the preliminary sketches of the application interface. The protocol for this focus group, which can be found in Appendix E3, was semi-structured with several questions used to stimulate discussion. Items from the list of requirements were read out and explained to the participants, who then were given opportunities to comment on them based on their own experiences. Some items, such as the availability of resources, were more important to the participants and took more time to discuss, while others were only briefly mentioned. Near the end of the session, printouts of the application sketches were distributed and the participants commented on the data presentation and the ease of understanding the interface.

3.4 Data Analysis

The study included two phases of data analysis, each following a data collection stage. The first data analysis phase used exploratory qualitative content analysis and focused on coding and extracting themes from the data collected in the in-depth interviews. This was done using the data analysis spiral method described by Creswell (2013, p. 182–183). NVivo 10 software was used to facilitate the coding.

A hierarchal scheme of needs was sketched out, then individual needs were displayed on a table and further analyzed. Possible ways of meeting those needs were then brainstormed using participant recommendations, available literature, current computer and communications features, and the principles of user-centred design. These suggestions were subsequently refined into data, functional, and contextual requirements that were mapped to the list of needs and added to the table of requirements (Cooper, Reimann, & Cronin, 2007).

Participant characteristics were laid out in table format and used to derive user personas using Miles, Huberman, and Saldaña's (2014) recommendations for making inferences from data matrices. Microsoft Visio was then used to design a low-fidelity prototype of a mobile application that incorporated those solutions using the principles of Human-Computer Interaction design. The requirements and the mock-ups were reviewed with the focus group in the second, confirmatory, phase of data collection. The reactions and comments were analyzed thematically, and the findings were refined to create the formalized set of requirements and the sample design for an HIT application. The requirements were then tailored to the personas using the framework developed by Lottridge, Chignell, and Straus (2011) for systemically determining sub-group customization requirements.

3.5 Quality of Analysis

There were internal and external quality checks for this research meant to bolster the analysis and to improve the quality of the conclusions. The coding, analysis, and application design were monitored and double-checked by my supervisor, providing an internal check for the quality of the research and its findings. Furthermore, the second stage of data collection provided a built-in test for the interpretation of the data collected in the first stage, and served to refine and validate its findings, thus improving the study's internal validity. The study also tried to control for external validity through making sure the selection criteria reflected the qualities of the population under study, and excluding participants who had previous professional training in nursing or medicine, which might have biased the findings.

The reliability of the study findings was tracked by making sure the research questions were clear and directly connected to the study design. Furthermore, data from both informal caregivers and home care nurses was analysed using a framework derived from the available body literature. This allowed me to check that my findings displayed meaningful parallelism across the different data sources and were comparable with the available literature (Miles, Huberman, & Saldaña, 2014, pp. 310-315).

An important consideration to objective analysis is the influence of my professional history. As a registered nurse, I interacted with cancer patients and their informal caregivers, and was often in a position of providing teaching. While this did allow for a deeper scientific understanding of some of the aspects of this study, it also put my analysis at a risk for biases and possible preconceived notions. I tried to remain as objective as possible throughout all phases of this research, including the recruitment and interviewing of participants, and the analysis of the study data, and I made sure to write explicit notes about how each conclusion was reached, to make it available for verification later on. Moreover, since my area of expertise was inpatient critical care and my nursing experience took place in Lebanon, under a different health care system, the value of my professional experience for this research was debatable, since I had no prior experience with home care or the Canadian health care system prior to starting this research. This was the reasoning behind conducting the focus group with Canadian home care RNs, which helped supplement my understanding considerably.

CHAPTER IV: Results

The following section will present the results of each of the two stages of the study, including user personas, caregiver needs, and application requirements. Figure 3 below reflects the design of the study, previously displayed in Figure 2, and maps out the study results as they appear in this section

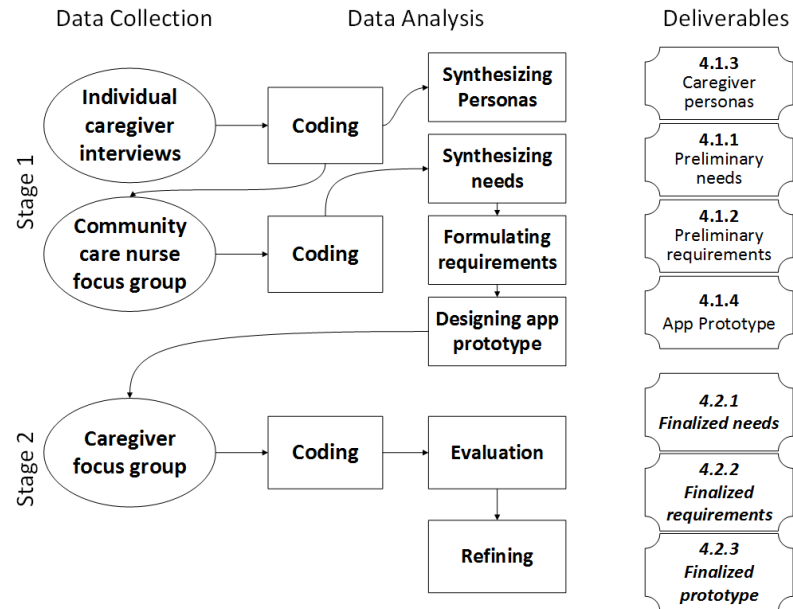


Figure 3: Map of Results Chapter

4.1 Stage I

4.1.1 Caregiver needs

A mixture of inductive and deductive coding was performed in this study. Deductive codes were used as a starting point and then edited according to the emergent data and supplemented with newer inductive codes. This process was highly iterative and codes were added, removed, renamed, and adjusted several times, as new information emerged from the constant comparison across all interviews and focus groups.

4.1.2.1 Initial coding scheme

A scheme of deductive codes was first formulated by combining the findings of two studies (Nijland, van Gemert-Pijnen, Boer, Steehouder, & Seydel, 2008; Travis, Bernard, McAuley, Thornton, & Kole, 2003) and two systematic reviews (Bee, Barnes, & Luker, 2009; Washington et al., 2011). This initial coding scheme is shown in Appendix G1, with the highest level consisting of four categories: User-friendliness, Implementation, Quality of care, and Information.

The first three categories all come from Nijland et al. (2008). *User-Friendliness* referred to the application's technical and design issues which make the presentation of the information more acceptable to the end-users; *Implementation* referred to the way applications can be incorporated into the pre-existing system, including the daily life of the end-users and the policies of the health care system under which they live; and *Quality of Care* referred to the actual caregiving components that deal with patient care issues (Nijland et al., 2008). The fourth section, *Information*, was imported from Washington et al. (2011), and dealt with the actual medical information that informal caregivers need to understand their patients' disease process and how the resulting illness came about.

The *Information* section further branched out to *Specific Information*, which referred to issues pertinent to each patient's unique conditions, and *General Information*, which contained three sub-categories of its own: *Basic Disease Information*, *General Treatment Options*, and *Availability of Services* (Washington et al., 2011).

The *Quality of Care* section was divided into eight sub-categories found in Bee et al.'s 2009 systematic review of the practical information needs of informal caregivers of cancer patients on home palliative care: *Medication and Pain Management*, *Physical Symptoms and Comfort*, *Nutrition*, *Personal Hygiene and Elimination*, *Positioning*, *Technical Equipment*, *Professional/Local Support*, and *Emergency Measures* (Bee et al., 2009).

The *Medication and Pain Management* section was further divided into four categories found in Travis et al.'s 2003 study that dealt with medication administration hassles among

family caregivers. *Information Seeking/Information Sharing* deals with learning about the medications themselves and their purpose and effects, *Scheduling Logistics* deals with coordinating medication administration schedules, *Safety Issues* deals with safety considerations of different medications, and *Polypharmacy* deals with managing complex medication regimens with multiple medications prescribed by different health care providers (Travis et al., 2003).

4.1.2.2 Second coding scheme

Before beginning the coding, the deductive coding scheme was reviewed to make sure it was granular enough and did not include any duplicates. *Professional/Local Support* was found to be similar to *Availability of Services* but considerably narrower in scope, and therefore it was blended into *Availability of Services* under the *Information* section. The second coding scheme is shown in Appendix G2.

4.1.2.3 Third coding scheme

A number of changes were made to the coding scheme after the first round of coding, as many nodes and sub-nodes were shuffled, renamed, or refined, with some inductive nodes emerging as well. It became apparent that *Availability of Services* did not fit neatly under either of the *Information* and *Quality of Care* nodes under their existing definitions. Moreover, this concept needed to include things that were not directly related to patient care, such as resources and services directed towards the caregiver. Hence, this section was moved to the first level of the coding scheme and re-defined to include all programs, services, and resources available to the caregiver through the local health care system.

Pain management and medication management consistently emerged as separate issues. While pain management was found to be closely related to *Physical Symptoms and Comfort*, it remained distinct enough to warrant its own node. Furthermore, pain assessment emerged as an important theme, especially for participants caring for sicker patients with an impaired ability to communicate the presence of pain. *Medication & Pain Management* was therefore separated into *Medication Management*, which retained all the

sub-categories from the Travis et al. paper, and *Pain*, which included both pain assessment and pain management issues.

Some inductive codes also emerged, covering a range of expressed and unexpressed needs. The deductive scheme was used to organize the preliminary deductive codes and allow the inductive codes to be placed within the existing framework of caregiver needs from the literature. The most common need that emerged among caregivers was the desire to know “what to expect”. This was communicated by all participants, usually verbatim, and referred not only to signs, symptoms, and treatment side effects – those items already included in the scheme under the *General* node – but also to possible complications and how the patient’s condition was expected to change as the illness becomes more advanced. Further analysis showed that this theme encompassed two separate unexpressed needs: *Illness Progression* and *Functional Decline*. Both of these needs were included as sub-categories under the *Information* node.

Illness Progression referred to the various complications that the patient might experience along the disease trajectory, including things like metastasis and the progressive worsening of their cancer symptoms. Information in this section was more in-depth and focused on what could be expected to happen in the future. In this way, it diverged from the information provided in *Basic disease information*, which included a cursory explanation of the disease pathology and focused on the theoretical aspects of the illness as well the patient’s current status without preparing the caregivers sufficiently for what was ahead.

Functional Decline, on the other hand, referred to the gradual reduction in the patient’s physical or cognitive functioning that resulted in them requiring assistance to perform their basic daily activities. Learning about functional decline was important for caregivers because most of their responsibilities involved compensating for a patient’s lost function, such as helping them move when their mobility was compromised.

Death and the process of dying also emerged as an important theme, closely related to the idea of knowing what to expect. Participants who had received verbal teaching or written material about expected changes in physical and functional status throughout the process of

dying reported feeling less anxious while witnessing their patient going through those changes. Despite this being a difficult and emotionally draining time, knowing what would happen next eased the participants' worries and allowed them to cope with the situation better. *The Process of Dying* was therefore included as a sub-section under the *Information* node. The third coding scheme is shown in Appendix G3.

4.1.2.3 Fourth coding scheme

After a few rounds of coding, a review of the hierarchal structure of the nodes and the contact summary sheets of the interviews revealed a problem with the structure of the *Medication Management* category. The specific four sub-categories of this node, *Information Seeking/Sharing*, *Safety Issues*, *Polypharmacy*, and *Scheduling Logistics*, did not seem to fit most of the quotes from the interviews regarding the administration of the medications. After a review of Travis et al., which was the source of these deductive codes, it was decided that these four sub-categories represented the hassles that caregivers might face while managing medications, rather than the component sub-categories of the entire *Medication Management* field. These quotes were instead coded directly at the higher *Medication Management* category, which seemed to fit better. However, since these hassles did represent important issues that needed to be addressed, they were later revisited and taken into consideration while generating the list of needs and requirements.

Another change deemed necessary was the renaming of the *Positioning* node to *Mobility*. Although that section already included ambulation in Bee et al.'s 2009 paper, its name seems more focused on passive repositioning in bed, which would disenfranchise at least two of the caregiver personas who might not consider assisting someone with walking as positioning. *Mobility*, on the other hand, encompassed all levels of assistance with walking, sitting, and other types of movements in which a patient could actively participate, as well as things that more passive patients needed such as lifting, turning in bed, and adjusting pillows.

After going through the transcripts a few more times, no new themes emerged and no new changes were deemed necessary. As such, it was decided that data saturation had been

achieved and the coding scheme was ready to be used for generating the application requirements. The fourth coding scheme is shown in Appendix G4.

4.1.2 Table of requirements

The fourth coding scheme was used to generate the table of requirements. The table was set up with three major columns: “Themes,” “Findings,” and “Implications.” Each of the need categories was entered in the “Themes” column, and study findings that supported its interpretation as a participant need were entered in the “Findings” column.

Recommendations for addressing those needs were entered in the “Implications” section, which sometimes included several levels of different suggestions that could be used to address the issues at hand. Each major category from the coding scheme, except *Implementation*, had a corresponding table. The nature of the *Implementation* category, however, was such that suggestions could be generated for the health care system under which the application could be used, but not for the application itself. The initial tables of requirements are shown in Appendix I and consist of Table 8.1, Table 8.2, and Table 8.3.

4.1.3 Personas

Five personas were created to represent subsets of the informal caregiver population based on patterns noted in experiences, skills, attitudes, and goals. Characteristics extracted from the interviews to determine the individual background and circumstances of each participant were mapped out on a spreadsheet. The spreadsheet was then searched for patterns that identify the differences in their educational needs following the Miles et al.’s recommendations for making inferences from matrices, including observing patterns and themes, making comparisons and contrasts, clustering, and making and verifying explicit conclusions (Miles et al., 2014, p. 117).

Upon examining the caregiving habits and the expressed needs of the interview participants, no difference was noted among different ages, genders, geographical settings, or educational levels. Furthermore, the level of comfort with computer technology did not seem to affect their information-seeking habits, as every one of the participants used

technology to search for information related to their caregiving role at one point during their caregiving experience. Even one participant who described herself as “completely computer illiterate” had asked her children to look up information online and print it out for her. Moreover, no significant differences were noted between participants who underwent the interview in person and those who completed via telephone.

The main differences found between the participants were related to the level of illness of their patients, as well as the level of involvement of the caregivers themselves in the care. The patient’s level of illness directly influences their functional status and their care needs, often dictating the information needs of the caregiver, and causing them to change along with the trajectory of the disease (Wackerbarth & Johnson, 2002). Following this finding, the second version of the Palliative Performance Scale (PPSv2) developed by the Victoria Hospice was used to measure the functional and performance decline in patients cared for by the interview participants (Victoria Hospice Society, 2006). The interview transcripts were re-examined and a new column was added to the spreadsheet to assign a PPS score to each patient. While this information might not be enough to accurately assess such a complicated matter, it does reflect the patient’s status as experienced by the caregiver.

Cancer Care Ontario separate the PPSv2 scale into three categories for their Palliative Care Collaborative Care Plans: Stable stage with PPSv2 80-100%, Transitional stage with PPSv2 40-70% and End of Life stage with PPSv2 0-30% (Cancer Care Ontario, 2013). This categorization was not very helpful for this study however, since by definition people with 70-100% scores are fully capable of caring for themselves and don’t need a caregiver. Three new categories were devised to create personas for this study: “low need” for scores of 50-60%, intermediate need for scores of 30-40%, and high need for scores of 10-20%. It is important to note that patient needs in this context are related to care, and distinguishable from caregiver needs discussed in this study.

Caregiver involvement was more difficult to measure since most studies that deal with caregiving intensity seem to use arbitrary thresholds in evaluating the time informal caregivers spend on caring for their patients (Nguyen & Connelly, 2014). For comparison purposes, the threshold used by Jacobs, Laporte, Van Houtven, & Coyte in their 2014 paper

was used for measuring the intensity of caregiving in this study, and a new column was added to the spreadsheet to assign a category to each participant. Therefore, participants were considered less-intense caregivers if they had provided less than 5 hours of care per week, mid-intensity if they provided 5-15 hours of care per week, and high intensity if they provided 15 or more hours of care each week (Jacobs, Laporte, Van Houtven, & Coyte, 2014).

Five different user personas were created using two dimensions (caregiving intensity and PPSv2 score), as displayed in Table 3:

- Less-intense low-need caregiver:
 - Spends less than 5 hours per week providing care
 - Assists patient with stable illness and a slightly decreased functional status (PPSv2 50–60%)
- Medium-intensity low-need caregiver:
 - Spends 5–15 hours per week providing care
 - Assists patient with stable illness and a slightly decreased functional status (PPSv2 50–60%)
- Medium-intensity intermediate-need caregiver:
 - Spends 5–15 hours per week providing care
 - Collaborates with health care providers to provide care to patient with worsening illness and a decreased functional status (PPSv2 30–40%)
- Medium-intensity high-need caregiver:
 - Spends 5–15 hours per week providing care
 - Collaborates with health care providers to provide care to patient during the last stages of life when the patient’s functional status is very low (PPSv2 10–20%)
- High-intensity caregiver:
 - Spends more than 15 hours per week providing care
 - Provides care throughout the patient’s worsening illness and decreased functional status (Patient’s PPSv2 60%–10%)

Table 3: User Persona Combination

PPSv2 \ Caregiving intensity	10-20%	30-40%	50-60%
<5 hours/week			LILN
5-15 hours/week	MIHN	MIIN	MILN
>15 hours/week	HI		

Three different levels were possible for each dimension, leading to nine total possible combinations of personas. However, people with a PPSv2 score 70% and above are fully functional and do not require a caregiver, while those with a score of 40% and below need a caregiver with a level of involvement greater than 5 hours per week. Therefore, the only persona to include less-intense caregivers deals with patients with a higher level of functioning. Moreover, high-intensity caregivers were found to have similar educational needs regardless of the level of care their patients needed, since they were involved in every aspect of their patient’s care and wanted to learn everything they could. Therefore, only one persona was developed to depict high-intensity caregivers.

After determination of the informal caregiver needs as discussed in the previous section, the next task was to discover how the personas differed from each other with respect to caregiver needs. The eight interview participants were entered into Table 3, which represents the five user persona categories. Some participants fit multiple personas as their experiences and the needs of their patients changed over the course of their caregiving trajectory. A caregiver can transition through multiple personas because patients with advanced cancer are often unstable and on a declining trajectory, meaning that caregiving needs will also change.

The table of requirements was then examined, and the needs of different personas were extrapolated from comparing and contrasting the needs of the participants they represented. The user personas created by LeRouge et al. (2013) were used as a template for the creation of the personas in this study. The detailed personas are included in Appendix F.

4.1.4 Application mock-up

A simple, low-fidelity prototype of the application was designed using Microsoft Visio[®]. The mock-up used a smart-phone template with simple introductory menus. It was not created to be an actual proposed design, but instead attempted to demonstrate what some of the information screens could be expected to look like if the list of recommendations was used for systems design. The application mock-up followed the coding scheme to create the major categories. Since the *Implementation* and *Presentation* refer to qualities of the application rather than its content, the *Information* and *Practical Caregiving* categories were the only ones displayed to the users. A favorites section was also added, as per the recommendation of the table of requirements. The interface was therefore separated into three parts, displayed in Figure 4:

- Info: Includes things under the *Information* node in the coding scheme
- Care: Includes things under the *Quality of Care* node
- Starred items: Allows users to assign a star symbol to items they want to read later or need quick access to

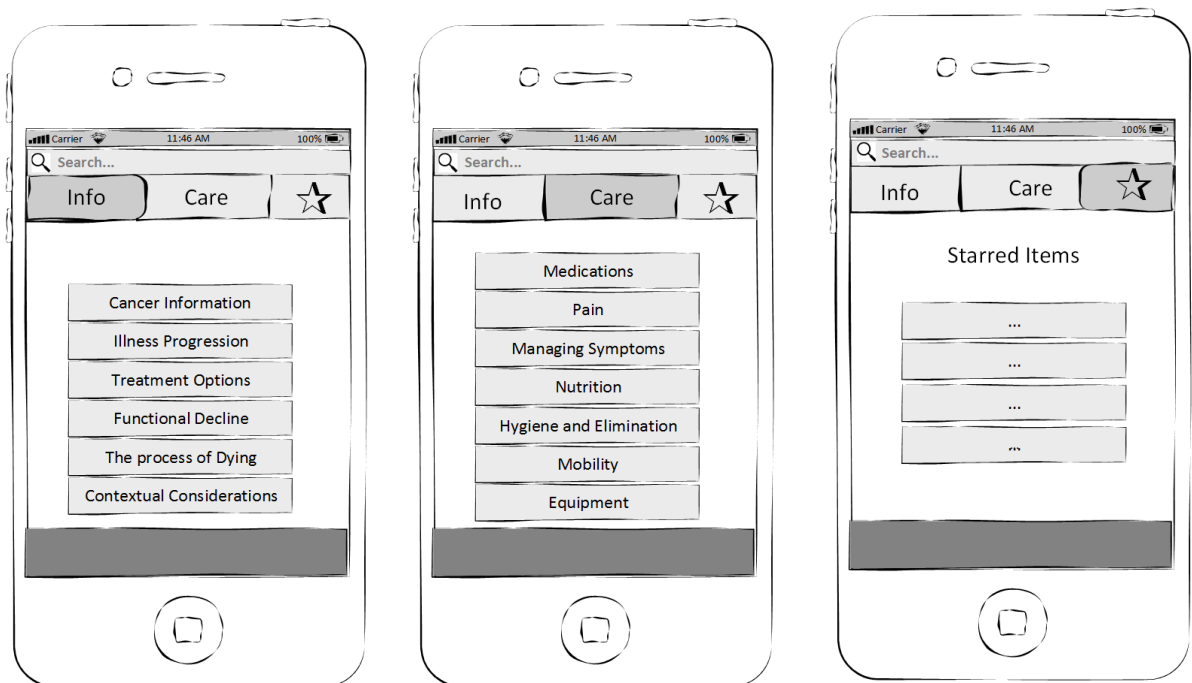


Figure 4: Introductory Menus of Application Prototype Interface

The prototype also included a brief depiction of what the *Pain* and *Medication* screens were expected to look like, since the table of requirements had some extra suggestions for how these two categories should be presented. The *Medication* section showed a display of the patient’s medication schedule, with the ability to click on each drug to read more about it. It also included a hyperlink to a database where the users can lookup other medications that they want to learn about. The *Pain* section included information about pain assessment, along with a simplistic version of the Wong-Baker Faces Pain Rating Scale. The pain and Medication interfaces are displayed in Figure 5, while the entire initial application mock-up can be found in Appendix H.



Figure 5: Pain and Medication Screens of Application Prototype Interface

4.2 Stage II

Phase II of the study consisted of a focus group discussion that enabled the findings of Phase I to be discussed and critiqued. Based on this focus group session, changes were made to the coding scheme, table of requirements, and application prototype.

4.2.1 Caregiver needs

The focus group participants agreed with the proposed categories of caregiver needs, so most changes made to the coding scheme at this point were simple quality checks, in order to make the titles of the different categories more relevant to their descriptions and their sub-categories. Some of the nodes were reorganized to achieve an optimal arrangement that grouped similar and related themes together.

Based on participant feedback, the *Quality of Care* section was renamed *Practical Caregiving* to make it clearer, and its sub-section *Technical Equipment* was simplified to *Equipment*. The section *User-Friendliness* was renamed as *Presentation*, since that has a stronger relation to the goals of this research, and had less technical and usability connotations, which are out of the scope of this study.

The *Information* section of the coding scheme retained its name, but many of its sub-categories were renamed and rearranged. To differentiate the medical information presented from the non-medical information, the *General* section was renamed *Medical*, and the *Specific* and *Illness Progression* categories were folded under it. Furthermore, the word *Specific* was found to be too vague, so the section was renamed *Contextual Considerations* to make it clear that this section deals with issues specific to each caregiver's context. Similarly, *Illness Progression* was not deemed different enough from *Functional Decline*, so it was changed to *Disease Trajectory*, which allowed the definition to be expanded to include remission. Moreover, *Basic Disease Information* and *General Treatment Options* were renamed *Disease Information* and *Treatment Options*, respectively, to make them more tangible in nature.

Due to the taboo nature of death and dying, it was considered at first that it might be more pragmatic to integrate *The Process of Dying* section into the *Functional Decline* section. When this suggestion was made in the focus group, however, the participants rejected the idea and reaffirmed that this was a very important topic that should be visible and easily available to all users. The section was therefore left in its original place under the *Information* category. The last adjustment made was arranging the categories in

alphabetical order, except for the nodes under the *Medical* section, which were kept in a more logical order that progresses from *Disease Information* to *Disease Trajectory* then *Treatment Options* and finally *Contextual Considerations*. The final code scheme, now a hierarchical structure of informal caregiver needs, is displayed below in Figure 6, and a large version is available in Appendix G5.

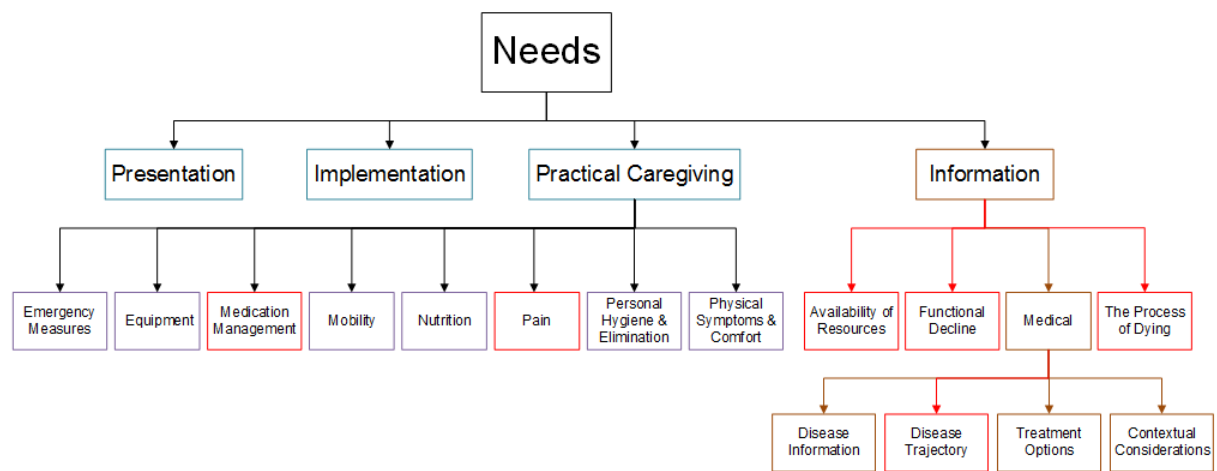


Figure 6: Informal Caregiver Needs

4.2.2 Application requirements

The content of the table of requirements was adjusted based on the feedback from the focus group. Alterations based on participant critique included adding information about organizations where different treatments were available, and the current waiting period for each, to the *Availability of Resources* table. Additionally, the large tables were split into one table per each category, and the “Themes” column was moved out of each table and used as an introduction instead. The titles of the remaining columns were changed to be more understandable; “Findings”, and “Implications” became, “Caregiver Needs”, and “System Design Implications”.

4.2.2.1 Information

The *Information* section, adapted from Washington et al. (2011), includes the information that informal caregivers need to understand their patients’ illness, treatment options, and

available resources (Washington et al., 2011), as well as complications to be expected. Individual needs in this section include: *Availability of Resources*, *Functional Decline*, *The Process of Dying*, and medical topics such as *Disease Information*, *Disease Trajectory*, *Treatment Options*, and *Contextual Considerations*. The needs are explained below and the design implications are presented in the subsequent tables.

4.2.2.1.1 Availability of Resources

Availability of Resources, displayed in Table 4.1, refers to information about the availability and methods of accessing different resources such as professional services or support.

<i>Table 4.1: Availability of Resources</i>	
Caregiver Needs	System Design Implications
<ul style="list-style-type: none"> • Some participants had difficulty navigating the health care system or even learning about different resources are available to them. Participants found the process of applying for each individual service long, difficult, and confusing. • Caregivers often had to travel with their patients to large hospitals or health centers for treatments that were not available locally. They often had to deal with different long and confusing waiting lists. • Some caregivers want to know about all resources available to them, even those they have to pay for out of pocket. 	<p>The application should provide a directory that caregivers can use to find information about all available resources including:</p> <ul style="list-style-type: none"> • All services, programs, and other resources available to the patient, including physical therapy, psychiatric consultations, occupational therapy, case management, and financial support. • Services available at the municipal, provincial, and national levels, as well as services provided by non-profit groups, charitable foundations, advocacy groups, etc. • Instructions to apply for the different services available, including which forms to fill out and expected waiting periods. • Locations and organizations where different treatments or services are available, along with the current waiting period for each. <p>Ideally, the application should provide information about all services available to the caregiver, even those not covered by their provincial health plan.</p> <ul style="list-style-type: none"> • The application could include coverage information of different private insurance plans available. The specific plan the patient is covered by could be loaded into the application during the initial set-up process. • Available services could be separated according to methods of payment, (“Covered” “Partially Subsidized” and “Out-of-Pocket” categories).

Table 4.1: *Availability of Resources*

Caregiver Needs	System Design Implications
<ul style="list-style-type: none"> • Obtaining, recording, and managing contact information of different health care professionals or organizations is one of the major roles of informal caregivers. • Many caregivers prefer to speak directly to someone who can help or provide explanation. • Some caregivers wrote regular notes or progress reports to keep health professionals informed about the patient’s condition. 	<p>The application should contain a directory of contact information for different provincial and regional health services.</p> <p>It should also contain a way for users to access their most frequently used contact details quickly instead of having to search a directory each time they are needed.</p> <ul style="list-style-type: none"> • This could be done by creating a list of favourites to which contacts can be added from the directory. • This list should be available on a separate screen for quick access. • There should also be a progress report section, where caregivers write their observations or record developments. These notes should be automatically assigned a timestamp. <p>Ideally, the caregiver would also be able to call health care professionals, or representatives of their health care system, directly from their mobile application.</p> <ul style="list-style-type: none"> • Other options, such as communicating with health professionals via short text messages or even links to a nursing hotline could also be useful. • Depending on the specific health care system and its available services, this feature could be something as simple as redirecting the user to the general inquiries number of the Community Care Access Centre of their Local Health Integration Network.
<ul style="list-style-type: none"> • Participants wanted to know about services directed towards caregivers, such as counselling, support groups, and other things that could help them care for themselves. 	<p>The application should include links to resources directed towards informal caregivers such as:</p> <ul style="list-style-type: none"> • General information about informal caregiving, its value, its scope, and what caregivers should and should not be expected to do. • A checklist of helpful topics for caregivers to learn, modelled after the needs uncovered in this research. • Advice and instructions on how to avoid caregiver burnout. • Local programs such as caregiving support groups and workshops.

Caregiver Needs	System Design Implications
	<ul style="list-style-type: none"> Local programs that provide respite care or aid with some of the caregiving responsibilities. Availability of paid or unpaid leave options, as well as provincial or federal programs that provide financial support to family caregivers.
<ul style="list-style-type: none"> Many participants mistrust what they read on the Internet and prefer information found on official-looking websites that they feel are more trustworthy. 	<p>Each section of the application should provide succinct information, with links to resources that would enable the caregivers to read further about the subject.</p> <p>The resources would likely be trusted implicitly by the caregivers since they would be provided by a proxy of the health care system, so the developers of the application should make sure to link to trustworthy sources that provide up-to-date information that is rooted in evidence-based practice.</p>

4.2.2.1.2 *Functional Decline*

Functional Decline, displayed in Table 4.2, refers to information about the gradual reduction in the patient’s physical and cognitive functioning, which leaves the patient requiring assistance in performing increasingly basic activities of daily living.

Caregiver Needs	System Design Implications
<ul style="list-style-type: none"> Most of the responsibilities of the participants revolved around compensating for their patient’s lost functions, such as independent mobility or the ability to manage their own medication protocol. Patients’ functional decline often caused a lot of stress for both the patients and their caregivers 	<p>The application should contain information about functional decline including:</p> <ul style="list-style-type: none"> Its causes and the patterns it usually follows. Different ways of measuring it, such as the Palliative Performance Scale or the Karnofsky Scale. Methods of dealing with it or slowing it down. Safety considerations for people with a diminished functional state, such as risk of falling.

4.2.2.1.3 Disease Information

Disease Information, displayed in Table 4.3, refers to information about etiology, pathology, diagnosis, and prognosis considerations of different types of cancer.

Caregiver Needs	System Design Implications
<ul style="list-style-type: none"> • Most participants were interested in learning about cancer: how cancer occurs, its symptoms, and what the different stages of cancer mean. • They were also very interested in prognosis and how prognosis is measured. 	<p>The application should include a general explanation of what cancer is and how it occurs, along with more specialized descriptions of different aspects of cancer and pertinent details including:</p> <ul style="list-style-type: none"> • A section that explains the types of cancer organized by cell type. • A section that explains metastasis and the different stages of cancer. • A section that explains different diagnostic procedures for different types of cancer. This should ideally include an explanation of the invasiveness and risk factors associated with some diagnostic methods, as well as the expected length of time to reach a diagnosis. • A section that explains remission and methods of measuring prognostic factors. This would include different prognostic considerations for certain types of cancer, such as age, gender, and medical history. • An alphabetical list of the different types of cancer classified according to their location, with a separate section for each item on the list detailing the etiology, risk factors, pathology, signs and symptoms, diagnostic procedures, prognostic considerations, and common treatments. <p>Each section should be brief but comprehensive and contain links to information resources that caregivers can peruse if they desire more detailed information.</p>

4.2.2.1.4 Disease Trajectory

Disease Trajectory, displayed in Table 4.4, refers to information about the pathology and resulting symptoms of worsening cancer as well as the various complications the patient might go through due to treatment, as the disease itself becomes more vicious, or remission is achieved.

<i>Table 4.4: Disease Trajectory</i>	
Caregiver Needs	System Design Implications
<ul style="list-style-type: none"> Participants were interested in learning about what they and their patient should expect from the cancer, including things like the progressive worsening of cancer symptoms and the complications that could result from the cancer or its treatments. 	<p>The application should contain an explanation of common trajectories that different types of cancer are likely to follow and the signs and symptoms expected at each stage.</p> <p>It should also contain information about complications of advanced cancer or cancer treatments, the signs and symptoms that accompany those complications, and their treatments.</p>
<ul style="list-style-type: none"> Many caregivers were unclear about what metastasis is, how it can occur, and which organs it can affect. 	<p>The application should explain the concept of metastasis, along with its etiology, pathology, and the usual patterns it follows.</p>
<ul style="list-style-type: none"> Participants wanted to learn how remission is determined and what the chances of recurrence were for different types of cancer. 	<p>The application should include a section that explains how remission is determined for different types of cancer and what factors can influence it. It should also explain recurrence, how it differs from progression, and its treatment options.</p>

4.2.2.1.5 Treatment Options

Treatment Options, displayed in Table 4.5, refers to information about the different options available for treatment of patients, and the likely effects and side-effects of each treatment.

<i>Table 4.5: Treatment Options</i>	
Caregiver Needs	System Design Implications
<ul style="list-style-type: none"> Participants wanted to know about the different treatments available for their patients, and how effective each option was likely to be. 	<p>The application should contain information about the most common treatments for the different types of cancer including:</p> <ul style="list-style-type: none"> Detailed explanation of what each treatment entails.

Table 4.5: *Treatment Options*

Caregiver Needs	System Design Implications
<ul style="list-style-type: none"> • Participants were often busy keeping up with different treatment schedules. They also wanted to be informed about what each treatment entailed, including time commitments and travel requirements. 	<ul style="list-style-type: none"> • The differences between each treatment, including availability in different locations, time needed for administration, level of invasiveness, associated side effects, and how effective it has proven to be in different scenarios. • Links to more advanced information, such as different evidence-based chemotherapy protocols.
<ul style="list-style-type: none"> • Many of the symptoms with which cancer patients and their family caregivers must deal are side effects of chemotherapy, radiation, surgery, or other treatments. • Different treatment options often entail different side effects or complications. 	<p>The application should include information about common side effects of cancer treatments, with more in-depth explanations of the most common effects and different ways they are generally treated or dealt with.</p> <p>It should also mention special precautions for patients undergoing different treatments, such as avoiding interaction with children or pregnant women after a radiation treatment, and avoiding tattoos, piercings, or dental work during chemotherapy cycles.</p>
<ul style="list-style-type: none"> • Nurses often deal with caregivers and others who are unsure of what palliative care entails and what its scope is. 	<p>The application should provide detailed explanations about palliative care including:</p> <ul style="list-style-type: none"> • Its definitions and goals. • Everything it entails, including different types of symptomatic treatments. • Its scope and its limits. <p>Ideally, this will also contain an emphasis on how palliative care and curative care are different approaches that are nevertheless compatible with each other.</p>

4.2.2.1.6 Contextual Considerations

Contextual Considerations, displayed in Table 4.6, refers to information tailored to individual caregiver needs.

Caregiver Needs	System Design Implications
<ul style="list-style-type: none">• Each cancer patient had their own unique circumstances that governed their condition. This means that their caregiver would have to learn about topics that were unique to that case and not shared by other caregivers.	<p>The application should contain sections that briefly discuss special circumstances, such as:</p> <ul style="list-style-type: none">• Common comorbidities, such as diabetes, which could affect the type of treatment prescribed or the patient’s response to treatment. Moreover, medications the patient may already be on could interact with cancer treatments or palliative therapies.• Rare conditions, treatments, and complications that not all patients go through or are too rare to be included in the main sections.• Information about clinical trials, what they involve, how they are usually conducted, ethical considerations, and whether they are financially covered or involve out-of-pocket payment. <p>Since not everything can be covered in the application, there should be links to topics that are rare or too specific.</p>

4.2.2.1.7 Process of Dying

Process of Dying, displayed in Table 4.7, refers to information about everything related to the process of dying, including the decline in the patient's health and functional status, and the first stages of the caregiver's bereavement.

Table 4.7: Process of Dying	
Caregiver Needs	System Design Implications
<ul style="list-style-type: none"> • Most caregivers are interested in learning about the signs of an impending death so they can know what to expect to happen. • Informal caregivers of palliative patients often have a hard time facing the impending death of their loved one and have started the process of bereavement earlier than usual. • Some people are unfamiliar with the legal and practical issues that need to be dealt with in preparation for, and after, a person's death. 	<p>The application should contain a brief description of the process of dying, including:</p> <ul style="list-style-type: none"> • The trajectory and the different stages of the process of dying. • The signs and symptoms of an impending death. • The changes that happen to a person's body when they pass away. <p>Ideally, the application should provide links to articles that discuss the subject in depth as well.</p> <p>The application should also include information about the different stages of bereavement and methods of coping, as well as links to local resources, programs, and support groups that deal with bereavement.</p> <p>The application should contain a list of details to be considered when a death is expected or after it occurs, including:</p> <ul style="list-style-type: none"> • Making a last will and testament. • Obtaining a medical certificate of death • Posting an obituary. • Making funeral arrangements.

4.2.2.2 Practical caregiving

The *Practical Caregiving* section was adapted from Nijland et al.'s *Quality of Care* section (Nijland et al., 2008). It refers to practical information needed to learn how to care for the patient in a safe and effective manner. Individual needs found in this section are:

Emergency Measures, Equipment, Medication Management, Mobility, Nutrition, Pain, Personal Hygiene and Elimination, and Physical Symptoms and Comfort. The needs are explained below and the study recommendations are presented in tables.

4.2.2.2.1 Emergency Measures

Emergency Measures, displayed in Table 5.1, refers to recognizing signs of life-threatening and non-life-threatening emergencies, providing emergency measures, and managing emergency contacts.

Table 5.1: Emergency Measures	
Caregiver Needs	System Design Implications
<ul style="list-style-type: none"> • Some participants faced experiences that required them to call an ambulance or a health care professional to deal with symptoms or incidents that were not part of the patient’s initial illness, such as uncontrollable bleeding or the patient sustaining a fall. • Nurses indicated that some caregivers and even some health care professionals were often unsure of the extent to which patients with a DNR should be treated in an emergency situation. 	<p>The application should include instructions on what to do in different emergency situations, including:</p> <ul style="list-style-type: none"> • When situations can be handled by the caregiver alone and when immediate help should be sought. • Handling common threats like a wound opening, a fall, or choking on food. • Which health care providers to contact in less urgent situations when immediate medical attention is not needed. <p>The application could include an interactive component that guides the caregivers through managing an emergency situation step-by-step, in a manner similar to instructions provided by Automated External Defibrillators.</p> <p>Ideally this application should also contain information about the scope of palliative care and what can be done for a DNR patient in cases of unanticipated deterioration or non-life-threatening injuries.</p>

4.2.2.2.2 Equipment

Equipment, displayed in Table 5.2, refers to everything related to medical aids, devices, and equipment, including procurement, handling, training, and proper use.

Caregiver Needs	System Design Implications
<ul style="list-style-type: none"> • Many informal caregivers need to handle medical devices or equipment at some point, such as walking aids, wheelchairs, hospital beds, medication pumps, oxygen generators, and blood glucose meters. • Some informal caregivers have to handle medical tubes and supplies, such as catheters, feeding tubes, and wound dressings. 	<p>The application should contain a section detailing the different types of medical equipment and supplies including:</p> <ul style="list-style-type: none"> • A description of different equipment, devices, and supplies and the purpose of each. • Instructions for using the equipment in the relevant section according to function (e.g., wheelchair in mobility section, feeding tubes in nutrition section).
<ul style="list-style-type: none"> • Some participants had a hard time acquiring medical equipment for use at home. Common problems were lack of awareness of suppliers, sources, and financial costs. 	<p>The application should contain a brief explanation about the usual methods of obtaining medical equipment, such as buying from a supplier, buying second hand, renting, or rent-to-buy programs. It should contain links to sources of such equipment if possible.</p> <p>The application should also include a brief section on how to properly discard used supplies. Moreover, it should mention different options for disposing of excess unused supplies or old equipment after they are no longer needed, such as donating them to certain organizations.</p>
<ul style="list-style-type: none"> • Some caregivers reported confusion when they noticed that different nurses perform the same procedure in a slightly different way. 	<p>The application should include an explanation of the most important steps in a procedure, while noting that some people might vary in the other steps in the procedure depending on how they are most comfortable.</p>

4.2.2.2.3 Medication Management

Medication Management, displayed in Table 5.3, refers to everything related to medications such as consumer drug information, medication procurement, medication administration, and dealing with polypharmacy and complex drug schedules.

Table 5.3: Medication Management

Caregiver Needs	System Design Implications
<ul style="list-style-type: none"> • Many participants were interested in reading about the different medications their patients were taking, including chemotherapeutic drugs and drugs to control pain and nausea. 	<p>The application should contain a specialized consumer drug guide that includes common drug categories used by cancer patients, such as different chemotherapeutic agents, medications used to treat side effects, and other relevant products. Each drug should be explained thoroughly, including information on:</p> <ul style="list-style-type: none"> • Drug category, indications, dosage, methods of administration, and expected effects. • The different names that each drug goes by (chemical name, generic name, and all available trade names). • The drug’s safety profile (side effects, metabolism, and known interactions with food or other drugs). • Precautions to be taken with taking certain drugs (e.g., if the drug can cause excessive bleeding, then tattoos and dental procedures should be avoided).
<ul style="list-style-type: none"> • Some participants cared for patients who were able to manage their own medication regimens, but others had to handle the procurement, management, or even administration of their patients’ medications. 	<p>The application should include instructions on different methods of medication administration, including oral, topical, subcutaneous, inhalation, etc. Special instructions should be given for handling and administration of certain medications, such as:</p> <ul style="list-style-type: none"> • Best ways to crush oral drugs for patients who cannot swallow them. • Which pills can be crushed and which cannot, and should therefore be replaced for patients with problems swallowing. • Which subcutaneous injections need massaging of the injection site afterwards and for which drugs should massaging be avoided. • Best storage methods (e.g., which drugs need to be stored in the fridge, which drugs should be kept away from sunlight). • Expiry date considerations for different types of drugs.
<ul style="list-style-type: none"> • Cancer patients, especially those with chronic comorbidities like diabetes or kidney disease, often have very complicated medication protocols with multiple medications that are 	<p>The application should contain advice on the logistics of scheduling complicated medication regimens to ensure the optimal effects and avoid dangerous drug interactions. It should also touch</p>

Caregiver Needs	System Design Implications
sometimes prescribed by different physicians.	<p>upon managing refills for medications prescribed by different physicians.</p> <p>Ideally the application could contain a drug management tool that would:</p> <ul style="list-style-type: none"> • Help the caregiver log medication administration times. • Give specific instructions on how to administer each medication. • Allow the caregiver to write notes for specific medications (e.g., blood glucose level measurement before an insulin dose is given). • Send reminders about upcoming drug refills to prescribing physicians.

4.2.2.2.4 Mobility

Mobility, displayed in Table 5.4, refers to all levels of support with movement, such as assistance with walking, standing, or positioning a patient in bed.

Caregiver Needs	System Design Implications
<ul style="list-style-type: none"> • Mobility was the most common issue that arose in relation to practical caregiving, since this need arises even in patients with a high PPSv2 score. • Informal caregivers of mobile patients often assist them with ambulation and caregivers of weak or bedridden patients need to reposition them in bed. 	<p>The application should contain instructions, diagrams, and videos (or links to videos) that illustrate how caregivers can help patients with their mobility.</p> <p>Assistance with all levels of functions should be included:</p> <ul style="list-style-type: none"> • Walking, sitting, and other types of movements that a patient can actively participate in. • Things that more passive patients need like lifting, turning in bed, and adjusting pillows.
<ul style="list-style-type: none"> • Informal caregivers of bedridden patients or patients with low level of mobility often have to deal with bed sores, contractures, or other consequences of immobility. • Informal caregivers with weak patients sometimes have to handle patients falling and fall-related injuries. 	<p>The application should list and explain the different consequences and complications of immobility. It should also include advice on how to prevent them, and different methods of reducing or treating them. The application should also discuss the dangers of patients falling, different methods of fall prevention, and what to do when a fall occurs.</p>

Caregiver Needs	System Design Implications
<ul style="list-style-type: none"> Caregivers often modify the home environment to fit the patients' mobility needs and ensure their safety, such as installing rails and ramps or moving patients' bedrooms to more easily accessible locations. Many caregivers have to deal with specialized medical equipment or aids that support patients or help lift/move them. 	<p>The applications should contain explanations of different types of home modifications that can be done to help patients carry on their activities of daily living as independently as possible.</p> <p>It should also include a description of all medical devices used to facilitate movement:</p> <ul style="list-style-type: none"> Mobility aids available to patients (canes, wheelchairs, walkers, etc.). Heavier equipment (lifts and hospital beds that the caregiver can use to reposition the patient in bed).

4.2.2.2.5 *Nutrition*

Nutrition, displayed in Table 5.5, refers to all levels of support with dietary health including preparation of meals, different feeding techniques, weight management, prevention of dehydration, management of appetite loss, and nutritional advice.

Caregiver Needs	System Design Implications
<ul style="list-style-type: none"> Providing meals or nutritional support is one of the major responsibilities of family caregivers. Additionally, informal caregivers of cancer patients and/or palliative patients have to deal with special diets and different feeding techniques. 	<p>The application should contain information about different dietary needs of cancer patients, and how these needs can be met:</p> <ul style="list-style-type: none"> Different methods and techniques of providing meals and feedings, depending on the patient's individual needs. Different nutritional supplements or alternative diets. Devices or tubes that might be used to administer feeding if the feeding can't be provided orally. <p>The application should also inform caregivers about special considerations for cancer patients:</p> <ul style="list-style-type: none"> Nutritional complications (e.g., malnutrition and dehydration). How to deal with common symptoms and side effects that affect eating (nausea, impaired swallowing, etc.).

4.2.2.2.6 Pain

Pain, displayed in Table 5.6, refers to knowledge of different pain types, methods of assessment, and different methods of management.

Caregiver Needs	System Design Implications
<ul style="list-style-type: none"> • Pain and pain management are major concerns of family caregivers. • Caregivers of patients with an impaired ability to communicate worried that they might be unable to detect when their patient was in pain, and thus their pain could be left untreated. • Home care nurses stated that pain management was one of the most common concerns of family caregivers of dying patients. They also noted that poor pain management generated feelings of guilt or helplessness and often interfered with caregivers' ability to cope with the situation. 	<p>The application should contain a section dealing with pain and pain management in detail including:</p> <ul style="list-style-type: none"> • Common causes of pain for cancer patients. • Different ways to assess pain, taking into consideration that patients could be at different levels of consciousness and communication. • Explanations of the different types and classes of pain medications, with their side-effects, methods of administration and special considerations. • Non-medical ways of treating some kinds of pain. • Links to articles discussing pain and pain management in palliative care at length.

4.2.2.2.7 Personal Hygiene and Elimination

Personal Hygiene and Elimination, displayed in Table 5.7, refers to all levels of support with maintenance of hygiene, grooming, and regular elimination.

Caregiver Needs	System Design Implications
<ul style="list-style-type: none"> • Some caregivers had to provide assistance to patients with their hygiene and toileting. • Some caregivers had to cooperate with PSWs to provide full care of the patients' hygiene, toileting, and grooming. 	<p>The application should contain descriptions of the best ways to provide the patient with hygiene, grooming, and toileting needs, including instructions and explanations on:</p> <ul style="list-style-type: none"> • Helping a patient achieve toileting, bathing, and grooming as independently as possible. • Using and cleaning up after commodes, urinals, bedpans, catheters, and diapers for patients who need more assistance. • Proper methods of bathing in bed, mouth care, eye care, clipping nails, brushing hair, etc.

Table 5.7: Personal Hygiene and Elimination	
Caregiver Needs	System Design Implications
	Ideally, suggestions on how to avoid complications like rashes and urinary tract infections should also be included.

4.2.2.2.8 Physical Symptoms and Comfort

Physical Symptoms and Comfort, displayed in Table 5.8, refers to recognition and management of all symptoms of cancer or side-effects of treatment with the goal of maintaining optimal level of comfort.

Table 5.8: Physical Symptoms and Comfort	
Caregiver Needs	System Design Implications
<ul style="list-style-type: none"> • All participants expressed concern over the physical comfort of their patients. • Home care nurses stated that family caregivers usually ask them many questions about dealing with nausea, fatigue, and other such symptoms. 	<p>The application should include a list of symptoms that patients have to deal with including:</p> <ul style="list-style-type: none"> • Common symptoms (nausea and vomiting, mouth or skin sores and infections, shortness of breath, fatigue and weakness, edema, constipation or incontinence, confusion, drowsiness, etc.). • Full discussion of each symptom and its different treatments. <p>Ideally, the application should also include simple non-medical ways that informal caregivers can treat symptoms and provide comfort (elevating or massaging the legs to decrease edema, providing small quantities of bland food for nausea, etc.).</p>

4.2.2.3 Presentation.

The *Presentation* need was adapted from the *User-Friendliness* theme derived from Nijland et al.'s 2008 paper and corroborated by the interviews and focus groups. This theme deals with technical and usability issues such as the actual design of the application, which is out of the scope of this study, but it also deals with the presentation of the information and the application content, which is a subject for which this study can make recommendations.

Presentation, displayed in Table 6, refers to issues related to the presentation of the application content, as well as user-interaction and usability issues.

Caregiver Needs	System Design Implications
<ul style="list-style-type: none"> • Participants desire something easy to access and transport. • Most participants were adept at using a personal computer to obtain information, and some were comfortable using smart phones as well. 	<p>The application should be either a mobile (smart phone or tablet) application or a web-based application.</p> <p>Ideally, it should be a web-based application that could be accessed via a web interface, mobile web, and a dedicated mobile application.</p> <p>The application interface design should be similar to the design of websites and applications popular in today’s market:</p> <ul style="list-style-type: none"> • The web-based application can be developed using frameworks such as ASP.NET, HTML5, Eclipse using Java, or others preferred by the individual developers. • The mobile or smartphone version of the application can be developed with Eclipse using Java. • The Graphical User Interface should employ Human Computer Interaction conventions such as high-contrast, sans-serif fonts, clear and minimalistic design, intuitive navigation structure with a search function, etc...
<ul style="list-style-type: none"> • Ottawa is a bilingual city, and like most big cities in Canada, it is highly diverse and houses people of different backgrounds and cultures, speaking different languages. • Home care nurses often have to resort to crude or unverified web translations to communicate their teaching to family caregivers. 	<p>The application should be available in multiple languages.</p> <p>Ideally, it could first be developed in English and French, and then more languages would be included based on the frequencies of different languages in the relevant area’s population.</p>
<ul style="list-style-type: none"> • Caregivers actively seek information on the web that is easier to understand. • Some caregivers attempted to read difficult medical material, such as research articles and MRI reports. • Caregivers identified “using layman’s terms” as one of the qualities of a good 	<p>The application should use very simple language, and avoid most technical terms and medical jargon.</p> <ul style="list-style-type: none"> • It should be written for a 6th to 7th grade reading comprehension level, according to the guidelines of Medline Plus’ <i>How to Write Easy-to-Read Health Materials</i> (NIH, 2013).

Caregiver Needs	System Design Implications
<p>application, as well as the main reason for liking the explanations or written material provided by some health professionals.</p> <ul style="list-style-type: none"> • Some nurses directed family caregivers to applications and websites designed for health professionals because they were written in a relatively simple language. 	
<ul style="list-style-type: none"> • Some caregivers preferred to speak directly to health professionals instead of reading information. • Some caregivers wanted a simple way of communicating with health care professionals or managing their contact information. 	<p>The application should include interactive features and a way of communicating with providers.</p> <ul style="list-style-type: none"> • Communication networks suitable for the health care system and the geographic location under which the application is to be used would be optimal
<ul style="list-style-type: none"> • Different informal caregivers preferred different methods of education, including reading articles, browsing leaflets and brochures, talking directly to health care professionals, watching demonstrations, and viewing diagrams and other visual representations. 	<p>The application should include information presented in different ways including:</p> <ul style="list-style-type: none"> • Brief written material. • Diagrams and illustrations. • Short videos. • Links to more in-depth articles and videos. • Information print-view could also be available for users who don't like reading on a screen.

4.2.2.4 *Implementation*

According to Nijland et al. (2008), *Implementation* refers to the different methods by which the application can be incorporated into the existing realities of the informal caregivers' lives, such as their daily routines and the different policies of the health care systems they live in (Nijland et al., 2008). This theme was the most difficult to code, since it is not as directly obvious in the informal caregiver experience as other needs of a more informational or practical nature. It is important to note, however, that the application could not be developed or used without giving proper consideration to this need.

Much research in the Usability field focuses on integrating technology seamlessly into end users' lives. The context of how, when, and why the product will be used must be taken

into consideration before the design process starts, to ensure that it is helpful to the user and not an imposition that forces the users to adapt their own habits to fit the product (Cooper et al., 2007).

The recommendations made by this study under the *Presentation* need can be reiterated here. For ease of access and transportability, the application should be either a mobile (smart phone or tablet) application or a web-based application, and ideally should be a web-based application that could be accessed via a web interface, mobile web, and a dedicated mobile application. The operating systems and design languages/frameworks used should be the same as those used in other popular applications in the current market (Android OS, iOS, ASP.NET, Eclipse, Java, HTML5, CSS, etc.).

Another consideration that would help integrate the application into the caregivers' lives would be its use of layman's terms. Therefore, the application should be written for a 6th to 7th grade reading comprehension level, using simple language and avoiding most technical terms and medical jargon. Additionally, as it would be easier for informal caregivers to use an application in a language with which they are comfortable, the application should be available in multiple languages. For the caregiving population in Canada, starting with French and English would make it easier for caregivers from different backgrounds.

A more difficult *Implementation* issue is the integration of the application into informal caregivers' local health care systems. The resources, policies, and standard practices available under each health care system need to be taken into consideration during the design and dissemination process. Few recommendations can be made to address this issue, as they all depend on the party intending on using this research to develop an application for the use of informal caregivers of cancer patients on palliative care.

If the developers were a private group, independent of the health care system under which their application was to be used, they would have to integrate the policies and resources of that system into the content of the application. For example, if a financial subsidy was only available in a certain province, the application developed for a different province would not need to include it. The developers would also have to determine the sources of information

to be used, since different health authorities and institutes have different guidelines. Moreover, the application might be used as an independent reference that includes a directory of health care services, but would not be used to communicate with the health care providers.

However, if the developers were associated with the health care system, they might have the authority to amend certain policies or practices to make more features viable, and the application could be designed as one of the resources available to informal caregivers. It could then provide information vetted, and guidelines approved, by the health authorities themselves. It could also include features that communicate with the health care providers, schedule treatments, and follow up on the patient's health. If the local health system infrastructure is set up in a way that makes it difficult for local practices to be amended, the application might not be successful as a tool to provide support to informal caregivers. For example, it might not be possible for some CCACs to link caregivers to services and special offers provided by private manufacturers of medical supplements or supplies.

4.2.2.5 Needs according to user personas

The user needs and application requirements described above represent all uncovered needs of all informal caregivers of cancer patients on home palliative care. Tables 7.1, 7.2, 7.3, 7.4, and 7.5 describe how these needs can be adapted to the five different user personas formulated earlier. Note that all family caregivers share the same *Presentation*, *Implementation*, and *Availability of Resources* needs, thus everything listed in the requirements table for these needs applies for all personas. Since the personas also share similar *Information* needs, the main differences among the different personas are in the *Practical Caregiving* category.

Table 7.1: Needs of Less-Intense Low-Need Caregiver Persona

Table 7.1: Needs of Less-Intense Low-Need Caregiver Persona	
Caregiver Need	System Design Implications
<i>Medical</i>	<ul style="list-style-type: none"> • This section should be brief, but it should contain links to further information. • The <i>Contextual Considerations</i> section may be omitted, or included in a very brief manner.
<i>Emergency Measures</i>	<ul style="list-style-type: none"> • This section should be brief, but it should contain links to further information. • Information presented here should be primarily focused on recognizing signs of an emergency and calling for help.
<i>Pain</i>	<ul style="list-style-type: none"> • This section should be brief, but it should contain links to further information. • Most information here should be about pain management.

Table 7.2: Needs of Medium-Intensity Low-Need Caregiver Persona

Table 7.2: Needs of Medium-Intensity Low-Need Caregiver Persona	
Caregiver Need	System Design Implications
<i>Medical</i>	<ul style="list-style-type: none"> • This section should be brief, but it should contain links to further information. • The <i>Contextual Considerations</i> section may be omitted, or included in a very brief manner.
<i>Emergency Measures</i>	<ul style="list-style-type: none"> • This section should be brief, but it should contain links to further information. • Information presented here should be primarily focused on recognizing signs of an emergency and calling for help.
<i>Pain</i>	<ul style="list-style-type: none"> • This section should be brief, but it should contain links to further information. • Most information here should be about pain management.
<i>Medication Management</i>	<ul style="list-style-type: none"> • This section should include a consumer drug guide, and tools to assist with management of polypharmacy and complicated medication schedules.
<i>Mobility</i>	<ul style="list-style-type: none"> • This section should be brief, but it should contain links to further information. • Most information here should be about assisting the patient with walking, including things like fall precautions and home alterations.
<i>Equipment</i>	<ul style="list-style-type: none"> • This section should be brief, but it should contain links to further information. • Most information here should be about walking aids and venous high flow ports.

Table 7.3: Needs of Medium-Intensity Intermediate-Need Caregiver Persona

Table 7.3: Needs of Medium-Intensity Intermediate-Need Caregiver Persona	
Caregiver Need	System Design Implications
<i>Medical Functional Decline The Process of Dying</i>	<ul style="list-style-type: none"> • This section should be brief, but it should contain links to further information.
<i>Emergency Measures</i>	<ul style="list-style-type: none"> • This section should be brief, but it should contain links to further information. • Information presented here should be primarily focused on recognizing signs of an emergency and calling for help.
<i>Pain</i>	<ul style="list-style-type: none"> • This section should be brief, but it should contain links to further information. • Most information here should be about pain management.
<i>Medication Management</i>	<ul style="list-style-type: none"> • This section should include a consumer drug guide, and tools to assist with management of polypharmacy and complicated medication schedules. • Information about different methods of medication administration should be included, with special considerations for certain medications.
<i>Mobility</i>	<ul style="list-style-type: none"> • This section should be brief, but it should contain links to further information. • Most information here should be about moving the patient or changing their position in bed or chair, including fall precaution and home modifications.
<i>Equipment</i>	<ul style="list-style-type: none"> • This section should be brief, but it should contain links to further information. • Most information here should be about wheelchairs and other mobility devices, medication administration tools, and venous high flow ports.
<i>Nutrition</i>	<ul style="list-style-type: none"> • This section should be brief, but it should contain links to further information. • Most information here should be about special diets and administration of food. Prevention of choking, dehydration, and other dietary complications should also be included.
<i>Personal Hygiene and Elimination</i>	<ul style="list-style-type: none"> • This section should be brief, but it should contain links to further information. • Most information here should be about assisting the patient with maintaining hygiene, grooming, and a regular toileting schedule.

Table 7.4: Needs of Medium-Intensity High-Need Caregiver Persona

Table 7.4: Needs of Medium-Intensity High-Need Caregiver Persona	
Caregiver Need	System Design Implications
<i>Medical Functional Decline The Process of Dying</i>	<ul style="list-style-type: none"> • This section should be comprehensive. It should include everything in the requirements table. • It should also contain links for those interested in further information.
<i>Emergency Measures</i>	<ul style="list-style-type: none"> • This section should be comprehensive. It should include everything in the requirements table.
<i>Pain</i>	<ul style="list-style-type: none"> • This section should be comprehensive. It should include everything in the requirements table.
<i>Medication Management</i>	<ul style="list-style-type: none"> • This section should be comprehensive. It should include everything in the requirements table.
<i>Mobility</i>	<ul style="list-style-type: none"> • This section should be comprehensive, with links included for those interested in further reading. • Most information here should be about positioning the patient in bed and preventing the complications of immobility.
<i>Equipment</i>	<ul style="list-style-type: none"> • This section should be comprehensive. It should include everything in the requirements table.
<i>Nutrition</i>	<ul style="list-style-type: none"> • This section should be comprehensive. It should include everything in the requirements table. • Most information here should be about dietary supplements, special diets and administration of food. • Prevention of choking, dehydration, and other dietary complications should also be included.
<i>Personal Hygiene and Elimination</i>	<ul style="list-style-type: none"> • This section should be comprehensive. It should include everything in the requirements table. • Most information here should be about keeping the patient clean and well-groomed, and monitoring their elimination regularity.

Table 7.5: Needs of High-Intensity Caregiver Persona

Table 7.5: Needs of High-Intensity Caregiver Persona	
Caregiver Need	System Design Implications
<i>Medical Functional Decline The Process of Dying</i>	<ul style="list-style-type: none"> • This section should be comprehensive. It should include everything in the requirements table. • It should also contain links for those interested in further information.

Caregiver Need	System Design Implications
<i>Emergency Measures</i> <i>Pain</i> <i>Medication Management</i> <i>Mobility</i> <i>Equipment</i> <i>Nutrition</i> <i>Personal Hygiene and Elimination</i>	<ul style="list-style-type: none"> • These sections should be comprehensive. They should include everything in the requirements table.

4.2.3 Application prototype

The focus group participants responded positively to the diagrams that showed the low-fidelity design of the application. The only concern raised was that *Contextual Considerations* in the *Info* screen was not very understandable. This was a very valid concern, since writing the scientific name for that category was in breach of the *Presentation* recommendation that advises the writing to be at a 6th to 7th grade comprehension level. The label was renamed *Special Considerations*.

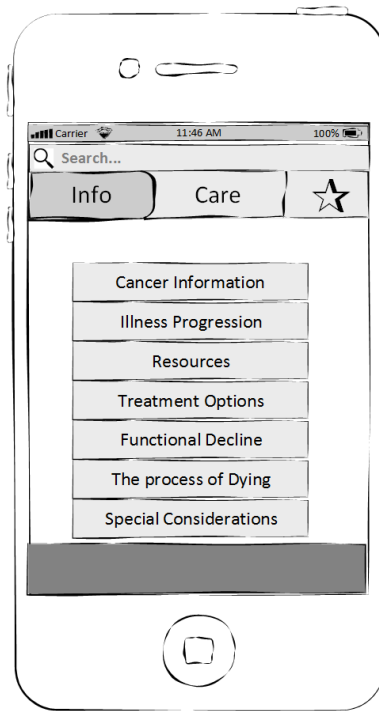


Figure 7: Adjusted Introductory Menu of the Info Screen

The progression of the application screens was deemed acceptable by the participants. They were asked their opinion about the Pain and Medication Management screens, which they were satisfied with. One comment mentioned confusion dealing with multiple names for the same drug, and this was used to adjust the recommendations for the application requirements in the *Medication Management* section. The application design was adjusted based on the focus group considerations and the final version is shown in Appendix H2.

CHAPTER V: Discussion

This research sought to use personas to discover how to package information into an HIT solution design in a way that is both usable and useful to informal caregivers of cancer patients on home palliative care. As such, it tried to answer three questions:

- What are the information needs of informal caregivers of terminally ill cancer patients receiving home palliative care in order to provide safe and effective care?
- How can we convert these information needs into system requirements for a Health Information Technology application designed to support informal caregivers of terminally ill cancer patients receiving home palliative care in a home or community environment?
- How can we tailor these requirements to different informal caregivers using User Personas?

In this section, I will discuss how the findings of this research answered those three questions in the context of the existing body of literature, and then provide recommendations for health care practice based on those findings. I will also discuss the limitations of this study, its contribution to knowledge, and future research for which it can provide a basis.

5.1 Informal Caregiver Needs

This study extracted the needs of the population into a hierarchical scheme that contains inductive findings from this research and deductive findings from the literature. The use of a deductive coding scheme was very important as this allowed for the inductive codes, some of them consisting of unexpressed needs derived from analysing the participants' experiences, to find a place among the needs already identified in the literature. The scheme is displayed in Figure 6, and splits informal caregiver needs into four categories: *Implementation*, *Presentation*, *Information*, and *Practical Caregiving*.

Implementation here refers to how the application can be incorporated into the informal caregiver's lives (Nijland et al., 2008). This stresses the importance of the application accommodating the end user's world instead of imposing an unwieldy change on their habits (Cooper et al., 2007), but also involves integrating the application into the health care system under which the caregiving experience takes place.

This study doesn't offer many new suggestions related to this category, since the data collection methods and the sources of data were not optimal for analysing this subject deeply. While it is out of the scope of this study to propose specific policies and standards of practice, available literature does suggest that a more nuanced understanding of the experiences of informal caregivers is needed for developing policies, practices, and interventions directed at them. Levine et al. recommended that policy makers consider four areas – information, training, program development, and finance reform – in order to improve informal caregiver training, involvement, and support (Levine et al., 2010).

Suggested recommendations for the *Presentation* category might be useful for addressing the integration of the application into the caregivers' own lives. The fields of Usability studies and Human Computer Interaction offer myriad solutions to make an application usable and non-intrusive. An additional consideration should be that applications created specifically to include information about resources, guidelines, and standard practices of a certain health care system are likely to be more relevant to the lives of caregivers in that region, and thus more likely to be accepted by the end-users.

The *Presentation* need refers to issues related to the presentation of the application content, as well as user-interaction and usability. Based on the data collected, it was found that informal caregivers needed something that was easy to access and transport, used simple non-technical language, and was available in multiple languages. They also preferred to obtain information in a variety of different methods including reading articles, browsing leaflets and brochures, talking directly to health care professionals, watching demonstrations, and viewing diagrams and other visual representations. Studies like Nijland et al. have also identified some of the same presentation issues, including language problems and inadequate navigation structures (Nijland et al., 2008).

The *Information* need refers to the theoretical information informal caregivers need to learn to make their caregiving experience easier, and included more inductive findings than all other categories. It includes details about the different aspects of the patient's illness, in addition to treatment options, available resources, and complications to be expected such as functional decline. This category also includes information about death, the process of dying, and bereavement. Much of the material in this category is the same as the teaching given to the patients and caregivers by physicians and other health professionals, since participants found it difficult to understand new information at the time of diagnosis. This is in line with the conclusions of Cecil et al., who found that caregivers had a hard time processing verbal information during stressful situations, and recommended that written information be made available for later reference (Cecil, et al., 2011), and also in line with Osse, Vernooij-Dassen, Schadé, & Grol, whose participants complained about the lack of options to reread information (Osse, Vernooij-Dassen, Schadé, & Grol , 2006).

The *Availability of Resources* was the most popular discussion topic among informal caregiver participants, with the most complaints being the difficulty of navigating the health care system and accessing available resources. Some participants were surprised at how many services and programs they could access and of which they had no previous knowledge. This need was mentioned before by Washington et al. and Bee et al., as well as Wong et al. (Bee et al., 2009; Washington et al., 2011; Wong, et al., 2002).

While *Functional Decline* was one of the inductive findings of this study, it had been suggested before by Kernisan et al. when they recommended including geriatric principles into the resources available for caregivers online (Kernisan, Sudore, & Knight, 2010). Many caregivers observed the gradual reduction in their patient's capabilities and wanted to know what to expect to happen in the next phases of the patient's illness. It is not surprising that this was an important issue for the caregivers, since most of their duties involve substituting for functions the patient has lost. Another inductive need was *The Process of Dying*. Due to the taboo nature of death and dying, and possibly also the desire to keep everything as optimistic as possible, the participants had a hard time finding information about the process of dying on websites, brochures, or books related to cancer

care or surgery. While some palliative care programs offered useful material on this subject, these were not easily accessible. Both caregiver and nurse participants in this research were of the opinion that including this information would improve caregiving quality as well as caregiver coping.

Disease Information, Treatment Options, and Contextual Considerations were all medical topics imported into the caregiver needs scheme from Washington et al. and then further developed by the emergent data. These needs were in line with the findings of other studies, such as Kernisan et al. (Kernisan et al., 2010). *Disease Trajectory* is an inductive finding in the *Medical Information* category. It arose from the analysis of the same recurrent theme that led to the development of the *Functional Decline* and *Process of Dying* needs, which is the caregivers' desire to know what is likely to happen next to their patients. Therefore, *Disease Trajectory, Functional Decline, and Process of Dying* were all unexpressed needs that were discovered in this study.

The last category on the informal caregiver needs scheme is *Practical Caregiving*. This category deals with the need to learn the hands-on activities required in everyday caregiving, such as administering meals or treating symptoms. The needs in this category were almost completely deductive, since they were all initially extracted from Bee et al.'s paper (Bee et al., 2009) but the data in this study led to some renaming and rearranging of these needs, most notably splitting the "*Medication & Pain Management*" need into two separate needs that dealt with one subject each. The final list of needs in the Practical Caregiving category were: *Emergency Measures, Equipment, Medication Management, Mobility, Nutrition, Pain, Personal Hygiene and Elimination, and Physical Symptoms and Comfort*.

5.2 Application Requirements

In order to translate the needs uncovered into actionable items, this study suggested different material, elements, and features that need to be present in an HIT application that aims to meet the needs of the study population. Furthermore, it presented a method of tailoring the application content to the needs of the different personas illustrated earlier.

The requirements were arranged in a table according to the individual needs to which they correspond. These requirements described the content that needed to be available to meet those needs, but also how that content should be arranged and presented in order to make it more suitable for the informal caregiver population. Some design features such as simplistic interfaces and different methods of navigation were also mentioned, but the application developers were given leeway when it came to the bulk of the actual interface design. Some of the requirements, such as the need for the application to be available in multiple languages, came through logical analysis of the needs. Others were suggested after consulting the literature, such as the requirement that the information be written for a 6th to 7th grade reading comprehension level, which is the recommendation of Medline Plus' *How to Write Easy-to-Read Health Materials* (NIH, 2013).

The requirements were further organised according to the user personas uncovered. Since the personas were arranged in ascending order, with each persona having increasingly more demanding responsibilities than the previous one, their additional needs therefore corresponded to more sophisticated requirements. This research provided a method of tailoring the application content to the different personas, which included gradually adding more content or making the existing content more comprehensive.

5.3 User Personas

This study uncovered important differences between the needs of the interview participants through analysis of their different caregiving experiences and the ways that their needs changed over time. Between the participants themselves, the main differences that seemed to influence their caregiving approaches were the needs of their patients and their own level of involvement in caring for these needs.

Five personas were created based on the variation between informal caregiver goals and needs among two axes: the functional and performance level of the patients as measured by the second version of the Palliative Performance Scale (Victoria Hospice Society, 2006), and the level of caregiving intensity as measured by the hours per week spent providing care (Jacobs et al., 2014). Five different combinations of these dimensions led to five

different personas: Less-intense low-need caregiver, Medium-intensity low-need caregiver, Medium-intensity intermediate-need caregiver, Medium-intensity high-need caregiver, and High-intensity caregiver.

This study followed the example of LeRouge et al.'s 2013 paper in creating the user personas. While LeRouge et al. used only one dimension (geographic location) to create two personas, this study went beyond that by using two dimensions to create five personas. Furthermore, LeRouge et al.'s two user personas were completely different from each other, with different attributes and user needs. In contrast, the personas generated by this study were more comparable, and are arranged on an ascending scale from those with the least amount of needs to those with the greatest. This schema allowed for the determination of each individual persona's needs and the corresponding application requirements to be also arranged in an ascending order in which each subsequent persona has additional needs and more sophisticated requirements than the previous one.

5.4 Recommendations

The findings of this research can be used by any party, public or private, interested in designing an application meant to provide interventions to informal caregivers of cancer patients. While the types and qualities of application content is indeed described by this research, developers have the leeway to choose the actual sources of information for their application, such as databases and guidelines they find trustworthy. The availability of some of the application features will depend on the goals of these application developers. For example, some public entities might decide to include resources provided by the private sector, while other might have local policies that prevent that. Private application developers, on the other hand, might decide to include only the resources provided by their affiliates or commercial partners. Additionally, the application has the potential to be expanded according to the wishes of its developers. Components like tracking tools may be added, and some bedside monitoring devices can be connected to the application to track things like blood pressure and blood glucose level.

Developers also have the option of making the application a mobile tool or a web-based application. This study recommends a web-based application that has a corresponding mobile application, so users can access the information they quickly if they need it but also be able to sit down and read it comfortably on a larger screen. This would also help resolve the digital divide problem likely to affect the ageing informal caregiver population, since some of them are reluctant to use some modern technologies like smartphone. This was reflected in my study population as many of my participants used computers regularly but didn't own a smartphone.

This research was conducted in the Champlain Local Health Integration Network, but it can be used to improve the conditions of the study population in most Canadian health care systems. It would be ideal for provincial ministries of health or Regional Health Authorities to sponsor the design and implementation of the kind of application recommended, using regional guidelines for palliative and community care. Health care centres such as hospitals, hospices, long-term care facilities, community health centres, or CCACs could then refer informal caregivers to the appropriate application as soon as they start home palliative care. Home care nurses would also be able to use the application while providing teaching, reinforcement, and referrals.

Application designers or other parties that mean to make use of this study have the option to either design five different applications to correspond to each persona, or to design one application with tailored features that activate or deactivate depending on which persona is using it. An important consideration is that an individual caregiver cannot be purely represented by one persona throughout the entire trajectory of the caregiving experience, but is likely to move up or down on the scale as circumstances change. For example, a MIIN caregiver might become MIHN if their patient's condition worsens, and a HI caregiver with a patient at 30% PPSv2 might become a MIHN if the patient is admitted to a palliative care unit, thus decreasing the intensity of the care provided by the caregiver. Interventions based on this research should therefore consider the personas as one of five possible states the caregiver can occupy. The best applications would take this into

consideration and be designed in a way that contains the same comprehensive information for everyone but adapts the interface based on the persona being catered for.

5.5 Limitations of the Study

This research has several limitations that need to be acknowledged. Time constraints and difficulties faced during the recruitment process led to sample sizes that were smaller than anticipated. Although saturation of data was indeed achieved, a few more participants would have made the validity of the findings more secure. Another limitation was the homogeneity of the informal caregiver sample, since ten out of eleven participants were Caucasian, and nine out of eleven spoke English as a mother tongue, which affects the transferability of the results to other communities. Moreover, the study and all the participants' caregiving experiences took place under the Ontario health care system, which might also influence the external validity of its findings.

Due to restrictions of time and resources, this study used a single focus group in the confirmatory phase, which is a less robust design than those that involve surveys or questionnaires with a larger number of participants. Additionally, the recruitment difficulties led to a caregiver focus group made up of only three people. Despite the participants' valuable critiques and contributions to the list of requirements as a whole, they were too few to represent the five different personas. The second phase of the research was thus unable to provide individual feedback relevant to each user persona.

Since this study needed to evaluate the level of caregiving intensity, it was measured by hours per week for all participants. This oversimplifies the complicated nature of caregiving intensity, which is influenced by many factors such as support systems, family history, and individual resilience. This might also be a significant limitation of the study and deserves to be researched more thoroughly in future studies.

The study used information obtained exclusively from informal caregivers and home care nurses. Since cancer patients, application developers, and other health professionals can also be considered stakeholders for this application, their exclusion is also an important limitation of this study. This is added to an intrinsic limitation in qualitative analysis, which

is that challenges in maintaining objectivity and reliability, since the coding and interpretation of the data was done by one person with biases and an individual perspective. Furthermore, the conversion of user needs to system design implications was done by an individual with a nursing and health informatics background, and some of the recommendations, especially the presentation features, might have been different had someone with a computer programming or application development background been consulted.

5.6 Contributions to Knowledge

This study enhances the understanding of the educational and support needs of informal caregivers of cancer patients on home palliative care, which feeds into the fields of health education, caregiver support, cancer care, palliative care, and home care. Previous studies such as Bee et al. (2009), Washington et al. (2011), and Wong et al. (2002) have touched on some of these subjects, but this study managed to combine them through focusing on a very specific population, and went beyond by discovering and describing unexpressed needs, such as the need for information on Functional Decline and the Process of Dying. Moreover, this study has demonstrated how the Needs Assessment method can be used in these fields to support the practice of participatory medicine.

This research also adds to the field of Health Informatics through seeking to translate the needs uncovered into content and design requirements for a Health Information Technology application that can be used by informal caregivers of cancer patients receiving palliative care at home. This study was also among the first to use personas to determine needs in the area of caregiver support, and thus can be used as a reference for future studies using personas in health care research.

5.7 Future Research

Applications developed according to study findings will need to undergo usability testing before they are made available for use. Future research could also focus on the effectiveness of such applications by empirically testing the difference between informal caregivers who use them and those who do not. Points of measurement would focus on the

safety and effectiveness of care as well as caregiver satisfaction and well-being. Moreover, some principles and findings of this study can be extended to caregivers of other patient populations, but similar research specific to these areas would still be needed. This study can also be a point of reference for anyone looking to use personas in future health care research, and the personas generated here can be used as templates for others.

CHAPTER VI: Conclusion

Informal caregivers are an important part of the health care system, but they continue to be undervalued and insufficiently supported. One of the major hurdles facing them is a lack of preparation for their caregiving activities, which is detrimental to the quality and safety of the care provided as well as the well-being of the caregivers. This research, based on participatory medicine and user-centred design, used a needs assessment method to uncover the educational and support needs of informal caregiver of cancer patients receiving palliative care at home, and to translate them into design requirements for the development of a Health Information Technology application.

Furthermore, this research was among the first to use user personas to determine needs in the area of caregiver support, providing a more realistic picture of informal caregiver needs among different trajectories of caregiving. The recommendations suggested by this research can be used to design HIT applications that can support family caregivers of oncology patients on home palliative care better than those available in today's market.

Many cancer patients on palliative and end-of-life care spend the majority of their time under home care (Bee et al., 2009). Using the findings of this research has the potential to increase the preparedness of informal caregivers of these patients by providing them with information and support, which can ultimately improve the home care atmosphere itself. This study should be therefore taken into consideration in the design and implementation of interventions targeting informal caregivers of cancer patients on home palliative care.

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Appendix A: Key Concepts from Literature

A1 - Caregiver Support

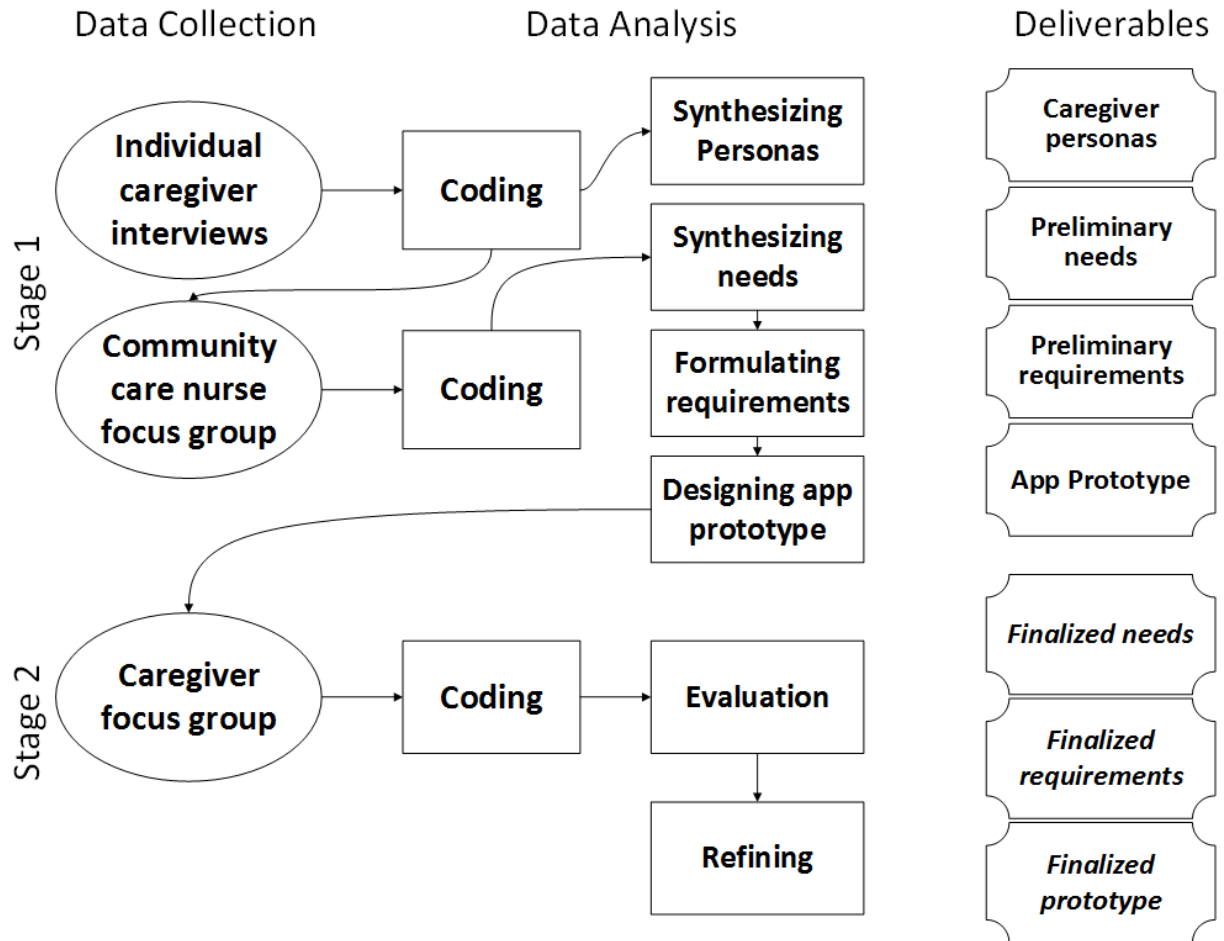
Research suggestions	<ul style="list-style-type: none"> • Need for research that explores caregiver training and support for medical tasks to achieve a fuller and policy-relevant understanding of their unmet needs 	Levine et al., (2010)
	<ul style="list-style-type: none"> • Need for future research to assess using technology to deliver effective interventions to caregivers 	Northouse et al., (2010)
Intervention suggestions	<ul style="list-style-type: none"> • Informal caregivers often feel insecure in their role, so caregiver interventions should focus on developing caregiver competence, preparedness, and confidence 	Harrop et al., (2014)
	<ul style="list-style-type: none"> • Integrating the teaching of different care skills throughout the continuum of care could have a major influence on decreasing unnecessary and costly re-hospitalizations and improving overall patient outcomes 	Levine et al., (2010)
	<ul style="list-style-type: none"> • Psychoeducational, skills training, and therapeutic counselling interventions aimed at caregivers reduce caregiver burden and improved self-efficacy, ability to cope, and quality of life. 	Northouse et al., (2010)
	<ul style="list-style-type: none"> • There is a reciprocal and significant link between patient and caregiver emotional distress. Evidence-based interventions for dealing with this problem are often are not applied in practice. • Need for seeking new ways to implement interventions that are based on an initial assessment of the needs of family caregivers. 	Northouse et al., (2012)
	<ul style="list-style-type: none"> • Using a guided-care model, wherein community nurses who work with primary care physicians provide guidance and support to family caregivers, improved the quality of chronic illness care delivered at home. • Caregiver interventions should be made more broadly accessible using a range of available communication methods. 	Wolff et al., (2010)

A2 – Caregiver Informational Needs

Types of information needed	<ul style="list-style-type: none"> • Disease information, pain and symptom management, home care services, and management of depression, weight loss, and appetite loss. • Physical needs like symptom control are valued most by informal caregivers. 	Cui et al, (2014)
	<ul style="list-style-type: none"> • Assistance with interpreting symptoms, knowing what to expect from disease or treatment, and learning practical care skills 	Kernisan et al., (2010)
	<ul style="list-style-type: none"> • All details of the relevant illness, including information such as disease information, prognosis, treatment options, what to expect at different stages of illness, and availability of different services • Up-to-date, practical, and accessible information. 	Washington et al., (2011)
	<ul style="list-style-type: none"> • Caregivers consider information needs more significant than emotional support needs. Information desired include diagnosis, treatment, and health plan coverage. 	Wackerbarth & Johnson, (2002)
	<ul style="list-style-type: none"> • Pain and fatigue management, and home palliative care resources. • Individual teaching and short written materials are the preferable mode of education. 	Wong et al., (2002)
Need for tailoring	<ul style="list-style-type: none"> • Need for a person-centred integrated care system that includes educational needs of both patients and their informal caregivers. 	Brazil et al., (2010)
	<ul style="list-style-type: none"> • Need for future research to investigate tailoring interventions to the needs of different types of caregivers based on gender, geographic location, and different points on the caregiving trajectory. 	Wackerbarth & Johnson, (2002)
	<ul style="list-style-type: none"> • Need for information provided at a range of different levels of health literacy. 	Washington et al., (2011)
	<ul style="list-style-type: none"> • Caregivers are more interest in a wider variety of topics than patients 	Wong et al., (2002)



Table 1.3: Using HIT to Deliver Support		
Caregivers already use HIT	<ul style="list-style-type: none"> • 34.5% of informal caregivers already use HIT solutions such as websites and mobile applications in their care activities. • The likelihood of using technology increases exponentially with the intensity of caregiving. • More than 70% of caregivers not currently using technology reported an interest in HIT and an intent to use it in the future. 	Zulman et al., (2013)
	<ul style="list-style-type: none"> • “Health care” is already one of the fastest growing categories of mobile applications for both iPhones and Android-powered devices, grossing more than 1.3 billion USD in 2012 alone. 	Transparency Market Research, (2013)
Need for research	<ul style="list-style-type: none"> • Need for research that explores the Internet’s potential for caregiver education and support. 	Kernisan et al., (2010)
	<ul style="list-style-type: none"> • Need for research that explores the effectiveness of using technology as a mode of delivering interventions to caregivers. 	Northouse et al., (2010)
Need to improve information currently available online	<ul style="list-style-type: none"> • Caregivers need more health information categories than currently available online, including categories about geriatric principles such as functional decline and cognitive impairment 	Kernisan et al., (2010)
	<ul style="list-style-type: none"> • Need for optimizing information available online so that it becomes accurate, timely, straightforward, readable, and patient-centred. 	Washington et al., (2011)
	<ul style="list-style-type: none"> • Caregivers complained of unfamiliarity with relevant programs and websites, distrust of information available on the Internet, and software complexity. 	Zulman et al. (2013)
Suggestions for which tools to use	<ul style="list-style-type: none"> • Videoconferencing, websites, and mobile applications may be the tools with the most potential for supporting patients and caregivers 	Demiris et al., (2011)

Appendix B: Study Design



Appendix C: Recruitment Material

C1- Recruitment Poster: Informal Caregiver Interviews



ARE YOU A FAMILY CAREGIVER OF A CANCER PATIENT?

We are looking for participants to take part in a study titled:
Using Health Information Technology to support informal caregivers of cancer patients at home: a needs assessment

You would need to:

- Be an adult
- Be fluent in English
- Not be a health care professional
- Be **currently** taking care of, or have previously taken care of, an **adult** family member or friend with advanced cancer.
- Have had your caregiving experience in a home setting.

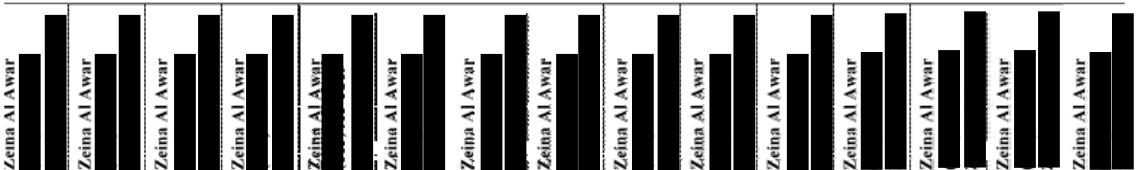
You would be asked to participate in an interview that's approximately 60 minutes long and can optionally be done over the phone.

Participants will be chosen on a first come-first served basis. In appreciation for your time, you would receive a gift card to Tim Hortons and any travel expenses you require will be covered.

For more information about this study, or to volunteer for participating, please contact:

Zeina Al Awar
Telfer School of Management, University of Ottawa
[Redacted]
[Redacted]

This study is a part of a master's thesis at the University of Ottawa. It has been reviewed by, and received ethics clearance from, the Office of Research Ethics at the University of Ottawa and the Research Ethics Board at Bruyère Continuing Care.





ARE YOU A FAMILY CAREGIVER OF A CANCER PATIENT?

We are looking for participants to take part in a study titled:
*Using Health Information Technology to support informal
caregivers of cancer patients at home: a needs assessment*

You would need to:

- Be an adult
- Be fluent in English
- Not be a health care professional
- Be currently taking care of, or have previously taken care of, an adult family member or friend with advanced cancer.
- Have had your caregiving experience in a home setting.

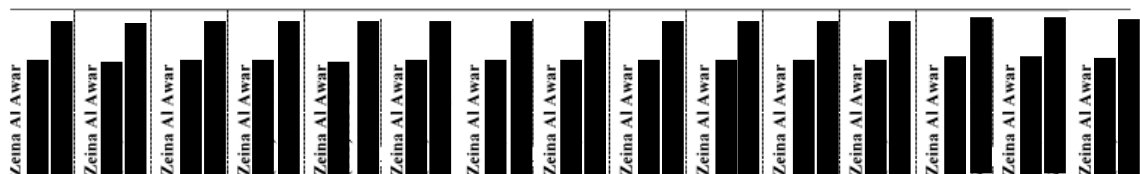
You would be asked to participate in a focus group that's approximately 90 minutes long.

Participants will be chosen on a first come-first served basis. In appreciation for your time, you would receive a gift card to Tim Hortons. Any travel expenses you require will be covered and refreshments will be served during the session.

For more information about this study, or to volunteer for participating, please contact:

Zeina Al Awar
Telfer School of Management, University of Ottawa

This study is a part of a master's thesis at the University of Ottawa. It has been reviewed by, and received ethics clearance from, the Office of Research Ethics at the University of Ottawa and the Research Ethics Board at Bruyère Continuing Care.



C3.1 - Letter for Participation: Informal Caregiver Interviews



Letter for Participation: Informal Caregiver Interviews

Title of the study:

Using Health Information Technology to support informal caregivers of cancer patients at home: a needs assessment

Principal Investigators:

Zeina Al Awar, MSc candidate, Telfer School of Management, University of Ottawa, Phone [REDACTED]
[REDACTED] email [REDACTED]

Dr. Craig Kuziemyk, PhD, Associate Professor, Director, MSc in Health Systems Program, Telfer School of Management, University of Ottawa, Phone (613) 562-5800 ext 4792, email kuziemyk@telfer.uottawa.ca

INTRODUCTION

You are invited to participate in an interview because you have experience acting as an informal caregiver of a cancer patient in a home setting.

Please read this letter carefully before deciding whether to participate. You may ask the investigators as many questions as you like.

OBJECTIVES

This research is funded by the School of Management Research Fund and is being conducted as part of a Master of Science thesis under the supervision of Dr Kuziemyk. It aims to investigate the components (i.e., features and information) that should be present in mobile applications designed to provide family caregivers such as yourself with information and support. It will explore the informational needs of caregivers and try to translate them into specific requirements that application developers can refer to while designing applications to be used during the home care process.

PROCEDURE

If you agree to participate in this study, you will be asked to meet with us for an interview of approximately 45-60 minutes in duration. It will be a one-on-one interview that will be audio-recorded and then transcribed to ensure accuracy. During the interview, we will discuss your experience as an informal caregiver, the information you need/needed, and the resources you use/used to obtain that information. We will also ask you some background questions (your employment history, level of experience with technology, etc...) to help us in our data analysis. You may choose not to answer any questions you are not comfortable with.

The interview will be conducted in English. The meeting will be set up at a mutually agreed upon location, and if any travel is required of you, we would be happy to reimburse your related expenses. We also provide a phone interview option, if you prefer.

RISKS AND DISCOMFORTS OF PARTICIPATION

It is not expected that you will suffer any risks due to participation in this study. However, your participation involves you talking about your experience caring for a terminally ill friend or family member, and this may make you uncomfortable. You have the choice not to answer questions that upset you and you may take breaks if you need them. If at any time you feel the need for counselling or follow-up, the principal investigator of this study (Zeina Al Awar) will be available to provide you with supports and services (resources) in the Ottawa Region.

C3.2 - Letter for Participation: Informal Caregiver Interviews



BENEFITS OF PARTICIPATION

There are no direct benefit to you from participating in this research. However, sharing your caregiving experience with us may contribute to improving the informational resources available to informal caregivers providing home palliative care to cancer patients.

VOLUNTARY PARTICIPATION AND WITHDRAWAL

Participants in our study are selected on a first-come, first-served basis. Participation is completely voluntary and confidential. If you do choose to participate, you can withdraw at any time or refuse to answer any questions that make you uncomfortable. If you choose to withdraw, all data gathered until the time of your withdrawal will be destroyed. Your decision to participate or not, or to withdraw, will have no impact on health care services available to you or your family. This study is not affiliated with the organization/agency through which you are recruited.

COMPENSATION

You will receive no monetary compensation for being in the study, however, if you choose to participate, you will receive a \$20 gift card to Tim Hortons and any travel expenses you require will be covered. If you choose to withdraw from the study, you will still receive the promised compensation.

CONFIDENTIALITY

All information you provide will be considered completely confidential. Information will be encrypted and stored securely in a password-protected file at the University of Ottawa in compliance with the university's ethical research protocol. No one outside the research team will have access to any information that can identify you. The data will be kept for 15 years and then deleted. Any hard copies produced during the study will be kept in a locked cabinet in the office of Dr Craig Kuziemsky at the University of Ottawa for 15 years and then shredded.

Data collected about you during the study will not identify you by name, but by a coded number. We will do everything in our power to keep everything you said confidential, and no information that can identify you will ever be revealed by the research team. Publications that result from this study will not contain your name, however, some of your quotations may be used anonymously. The University of Ottawa Ethics Board and the Bruyère Research Ethics Board may also review your study records for audit purposes.

QUESTIONS ABOUT THE STUDY

If you have any further questions about this study, please contact either members of the research team at the phone numbers or email addresses listed.

This study has received approval from the Office of Research Ethics at the University of Ottawa and the Research Ethics Board at Bruyère Continuing Care. If you have any questions about your rights as a research participant, please contact the Protocol Officer for Ethics in Research at the University of Ottawa at (613)562-5387 or ethics@uottawa.ca, or the Research Ethics Board Chair at Bruyère Continuing Care at (613) 562-6262 ext. 1420 or dkessler@bruyere.org.

Thank you for your time.

Yours sincerely,

Zeina Al Awar
Telfer School of Management
University of Ottawa



Craig Kuziemsky (Ph.D)
Telfer School of Management
University of Ottawa
(613) 562-5800 ext 4792
kuziemsky@telfer.uottawa.ca

C4.1 - Letter for Participation: Community Care Nurses



Letter for Participation: Community Care Nurses

Title of the study:

Using Health Information Technology to support informal caregivers of cancer patients at home: a needs assessment

Principal Investigators:

Zeina Al Awar, MSc candidate, Telfer School of Management, University of Ottawa, Phone [REDACTED] email [REDACTED]

Dr. Craig Kuziemyk, PhD, Associate Professor, Director, MSc in Health Systems Program, Telfer School of Management, University of Ottawa, Phone (613) 562-5800 ext 4792, email kuziemyk@telfer.uottawa.ca

INTRODUCTION

You are invited to participate in a focus group because you have experience dealing with, and providing education to, family caregivers of cancer patients in a home setting.

Please read this letter carefully before deciding whether to participate. You may contact the investigators with as many questions as you like.

OBJECTIVES

This research is funded by the School of Management Research Fund and is being conducted as part of a Master of Science thesis under the supervision of Dr Kuziemyk. It aims to investigate the components (i.e., features and information formats) that should be present in consumer health applications designed to provide family caregivers with information and support. It will explore the informational needs of informal caregivers and seek to translate them into specific requirements that application developers and designers can refer to in order to make their products more usable and useful.

PROCEDURE

If you agree to participate in this study, you will be asked to meet with us for a focus group interview of approximately 60-90 minutes in duration. The meeting will be set up at a convenient location, and refreshments will be provided. If any travel is required of you, we would be happy to reimburse your related expenses. The focus group will involve discussing the group's shared experience as community care nurses and your professional opinions on the informational needs of informal caregivers of cancer patients on home palliative care.

The focus group will be conducted in English. It will be audio-recorded to ensure accuracy. You may choose not to answer any questions you are not comfortable with. Please note that due to the interdependent nature of focus group transcripts, data cannot be withdrawn once the focus groups are completed.

BENEFITS OF PARTICIPATION

There are no direct benefit to you from participating in this research. However, your participation may contribute to improving informational resources available to informal caregivers providing home palliative care to cancer patients, which could increase patient comfort and safety.

C4.1 - Letter for Participation: Community Care Nurses



VOLUNTARY PARTICIPATION AND WITHDRAWAL

Participants in our study will be selected on a first-come, first-served basis. Participation is completely voluntary and confidential. If you do choose to participate, you can withdraw at any time or refuse to answer any questions that make you uncomfortable. Your decision to participate or not or to withdraw will have no impact on your career since this study is not affiliated with the organizations/agencies through which you are recruited.

COMPENSATION

You will receive no monetary compensation for being in the study, however, if you choose to participate, you will receive a \$20 gift card to Tim Hortons. Refreshments will be served during the focus group and any travel expenses you need will be covered. If you choose to withdraw from the study, you will still receive the promised compensation.

CONFIDENTIALITY

Since there will be other participants present during the focus group, complete confidentiality cannot be guaranteed. However, information discussed will not be of a personal or sensitive nature and you will not be asked to disclose any restricted patient information. Additionally, all participants will be asked to sign a confidentiality agreement before the interview starts.

All information you provide will be considered confidential by the research team. Information will be encrypted and stored securely in a password-protected file at the University of Ottawa in compliance with the university's ethical research protocol. No one outside the research team will have access to any information that can identify you. The data will be kept for 15 years and then deleted. Any hard copies produced during the study will be kept in a locked cabinet in the office of Dr Craig Kuziemyk at the University of Ottawa for 15 years and then shredded.

Data collected about you during the study will not identify you by name, but by a coded number. We will do everything in our power to keep everything you said confidential, and no information that can identify you will ever be revealed by the research team. Publications that result from this study will not contain your name, however, some of your quotations may be used anonymously. The University of Ottawa Ethics Board and the Bruyère Research Ethics Board may also review your study records for audit purposes.

QUESTIONS ABOUT THE STUDY

If you have any further questions about this study, please contact either members of the research team at the phone numbers or email addresses listed. If you are selected for the study, we will contact you to arrange the interview.

This study has received approval from the Office of Research Ethics at the University of Ottawa and the Research Ethics Board at Bruyère Continuing Care. If you have any questions about your rights as a research participant, please contact the Protocol Officer for Ethics in Research at the University of Ottawa at (613)562-5387 or ethics@uottawa.ca, or the Research Ethics Board Chair at Bruyère Continuing Care at (613) 562-6262 ext. 1420 or dkessler@bruyere.org.

Thank you for your consideration.

Yours sincerely,

Zeina Al Awar
Telfer School of Management
University of Ottawa



Craig Kuziemyk (Ph.D)
Telfer School of Management
University of Ottawa
(613) 562-5800 ext 4792
kuziemyk@telfer.uottawa.ca

C5.1 - Letter for Participation: Informal Caregivers Focus Group



Letter for Participation: Informal Caregivers Focus Group

Title of the study:

Using HIT to support informal caregivers of cancer patients at home: a needs assessment

Principal Investigators:

Zeina Al Awar, MSc candidate, Telfer School of Management, University of Ottawa, Phone [REDACTED]
email [REDACTED]

Dr. Craig Kuziemyk, PhD, Associate Professor, Director, MSc in Health Systems Program, Telfer School of Management, University of Ottawa, Phone (613) 562-5800 ext 4792, email kuziemyk@telfer.uottawa.ca

INTRODUCTION

You are invited to participate in a focus group because you have experience acting as an informal caregiver of a cancer patient in a home setting.

Please read this letter carefully before deciding whether to participate. You may ask the investigators as many questions as you like.

OBJECTIVES

This research is funded by the School of Management Research Fund and is being conducted as part of a Master of Science thesis under the supervision of Dr Kuziemyk. It aims to investigate the components (i.e., features and information) that should be present in mobile applications designed to provide family caregivers such as yourself with information and support. It will explore the informational needs of caregivers and try to translate them into specific requirements that application developers can refer to while designing applications to be used during the home care process.

PROCEDURE

If you agree to participate in this study, you will be asked to meet with us for a focus group interview of approximately 60-90 minutes in duration. Refreshments will be provided, and if any travel is required of you, we would be happy to reimburse your related expenses. The focus group will involve discussing the group's experience as family caregivers, and your opinions on caregiver informational needs during the care experience. The group will also be shown a preliminary design for a mobile application meant to provide information to informal caregivers of cancer patients on home palliative care and asked to comment on it and provide suggestions for improvement.

The focus group will be conducted in English. It will be audio-recorded to ensure accuracy. You may choose not to answer any questions you are not comfortable with. Please note that due to the interdependent nature of focus group transcripts, data cannot be withdrawn once the focus groups are completed.

BENEFITS OF PARTICIPATION

There are no direct benefit to you from participating in this research. However, sharing your caregiving experience with us may contribute to improving the informational resources available to informal caregivers providing home palliative care to cancer patients.

RISKS AND DISCOMFORTS OF PARTICIPATION

It is not expected that you will suffer any risks due to participation in this study. However, your participation involves you talking about your experience caring for an ill friend or family member, and this may make you uncomfortable. You have the choice not to answer questions that upset you and you may take breaks if you need them. If at any time you feel the need for counselling or follow-up, the principal investigator (Zeina Al Awar) will be available to provide you with supports and services (resources) in the Ottawa Region.

C5.2- Letter for Participation: Informal Caregivers Focus Group



VOLUNTARY PARTICIPATION AND WITHDRAWAL

Participants in our study will be selected on a first-come, first-served basis. Participation is completely voluntary and confidential. If you do choose to participate, you can withdraw at any time or refuse to answer any questions that make you uncomfortable. Your decision to participate or not or to withdraw will have no impact on health care services available to you or your family. This study is not affiliated with the organization/agency through which you are recruited.

COMPENSATION

You will receive no monetary compensation for being in the study, however, if you choose to participate, you will receive a \$20 gift card to Tim Hortons. Refreshments will be served during the focus group and any travel expenses you need will be covered. If you choose to withdraw from the study, you will still receive the promised compensation.

CONFIDENTIALITY

Since there will be other participants present during the focus group, complete confidentiality cannot be guaranteed. However, information discussed will not be of a personal or sensitive nature, and all participants will be asked to sign a confidentiality agreement before the interview starts.

All information you provide will be considered confidential by the research team. Information will be encrypted and stored securely in a password-protected file at the University of Ottawa in compliance with the university's ethical research protocol. No one outside the research team will have access to any information that can identify you. The data will be kept for 15 years and then deleted. Any hard copies produced during the study will be kept in a locked cabinet in the office of Dr Craig Kuziemyky at the University of Ottawa for 15 years and then shredded.

Data collected about you during the study will not identify you by name, but by a coded number. We will do everything in our power to keep everything you said confidential, and no information that can identify you will ever be revealed by the research team. Publications that result from this study will not contain your name, however, some of your quotations may be used anonymously. The University of Ottawa Ethics Board and the Bruyère Research Ethics Board may also review your study records for audit purposes.

QUESTIONS ABOUT THE STUDY

If you have any further questions about this study, please contact either members of the research team at the phone numbers or email addresses listed.

This study has received approval from the Office of Research Ethics at the University of Ottawa and the Research Ethics Board at Bruyère Continuing Care. If you have any questions about your rights as a research participant, please contact the Protocol Officer for Ethics in Research at the University of Ottawa at (613)562-5387 or ethics@uottawa.ca, or the Research Ethics Board Chair at Bruyère Continuing Care at (613) 562-6262 ext. 1420 or dkessler@bruyere.org.

Thank you for your time.

Yours sincerely,

Zeina Al Awar
Telfer School of Management
University of Ottawa



Craig Kuziemyky (Ph.D)
Telfer School of Management
University of Ottawa
(613) 562-5800 ext 4792
kuziemyky@telfer.uottawa.ca

Appendix D: Consent Forms

DI- Consent form for research participation-Interview



Consent form for research participation-Interview

Title of the study:

Using Health Information Technology to support informal caregivers of cancer patients at home: a needs assessment

I understand that I am being asked to participate in a research study about how to best design a mobile application that provides information and support to informal caregivers of cancer patients receiving palliative care at home. Details of this study has been explained to me by one of the principal investigators.

I have read the letter for participation and all my questions have been answered to my satisfaction. If I decide at a later stage that I would like to withdraw my consent, I may do so at any time.

I voluntarily agree to participate in this study and I agree to the use of my anonymous quotations in any publication that comes out of this research.

A copy of the letter for participation and the signed consent form will be provided to me. If I have any ethical concerns regarding my participation in this study, I may contact the Protocol Officer for Ethics in Research, University of Ottawa, 550 Cumberland Street, Room 154, Ottawa, ON K1N 6N5, (613) 562-5387 or ethics@uottawa.ca. I may also contact the Research Ethics Board Chair at Bruyère Continuing Care at (613) 562-6262 ext. 1420 or dkessler@bruyere.org.

Participant Name: _____ (Please print)

Participant Signature: _____

Date: _____

Investigator Statement

I have explained to the research participant all details of the abovementioned research study. To the best of my knowledge, the participant signing this consent form understands the nature, demands, risks and benefits involved in participating in this study. I acknowledge my responsibility for the care and well-being of the above participant, to respect the rights and wishes of the participant, and to conduct the study according to applicable ethical guidelines and regulations.

Name of Investigator: _____ (Please Print)

Signature of Investigator: _____

Date: _____

D2 - Consent form for research participation-Focus Group



Consent form for research participation-Focus Group

Title of the study:

Using Health Information Technology to support informal caregivers of cancer patients at home: a needs assessment

I understand that I am being asked to participate in a research study about how to best design a mobile application that provides information and support to informal caregivers of cancer patients receiving palliative care at home. Details of this study has been explained to me by one of the principal investigators.

I have read the letter for participation and all my questions have been answered to my satisfaction. If I decide at a later stage that I would like to withdraw my consent, I may do so at any time.

I voluntarily agree to participate in this study and I agree to the use of my anonymous quotations in any publication that comes out of this research.

I agree to keep the identities of my fellow participants and all comments made during this session confidential, and not discuss anything that happens during this focus group outside the meeting.

A copy of the letter for participation and the signed consent form will be provided to me. If I have any ethical concerns regarding my participation in this study, I may contact the Protocol Officer for Ethics in Research, University of Ottawa, 550 Cumberland Street, Room 154, Ottawa, ON K1N 6N5, (613) 562-5387 or ethics@uottawa.ca. I may also contact the Research Ethics Board Chair at Bruyère Continuing Care at (613) 562-6262 ext. 1420 or dkessler@bruyere.org.

Participant Name: _____ (Please print)

Participant Signature: _____

Date: _____

Investigator Statement

I have explained to the research participant all details of the abovementioned research study. To the best of my knowledge, the participant signing this consent form understands the nature, demands, risks and benefits involved in participating in this study. I acknowledge my responsibility for the care and well-being of the above participant, to respect the rights and wishes of the participant, and to conduct the study according to applicable ethical guidelines and regulations.

Name of Investigator: _____ (Please Print)

Signature of Investigator: _____

Date: _____

Appendix E: Study Protocols

E1.1 - Interview protocol

Interview Protocol

Introduction

Hello. Thank you for taking the time to speak to me.

As I told you before, I'm conducting this interview as a part of a research study aimed at developing a mobile application that helps family caregivers of cancer patients on comfort care learn how to perform their tasks properly in a home environment. As someone who's been in/is going through that role, I would really appreciate your input.

There are no right or wrong answers, and as I told you before, we can stop whenever you like and you don't have to answer anything that makes you uncomfortable. You can also take breaks if you need them.

You have already signed the consent form and agreed to be audio recorded. If at any time during the interview you would like to turn the audio recorder off, all you have to do is tell me.

Background

- 1) First of all, I would like to know a bit about you.
 - (a) In what year were you born?
 - (b) What is your marital status?
 - (c) Tell me about your educational background
 - (d) Tell me a little bit about your employment background
 - (e) What responsibilities other than caregiving do you have in your daily life?

Caregiving

- 2) Now I need to ask a few questions about your caregiving role and experience
 - (a) Tell me how you became a family caregiver (Clarification: relation to patient, history of illness progression).
 - (b) Please describe briefly your role and responsibilities as a caregiver

E1.2 - Interview protocol

- (c) How many people do you share the caregiving role with? How do you divide the caregiving responsibilities amongst yourselves.
- (d) Please describe a typical day in your life as a caregiver.
- (e) Describe how familiar you were with health or medical topics before you took on the role of a caregiver.
- (f) What medical topics did you have to familiarize yourself with after you became a caregiver? Give me an example of each.
- (g) Which care procedures did you have to learn to do? Did you have any difficulties? Describe the learning process of one of these procedures.

Caregiver teaching

- (h) Please describe the teaching you received from official sources. (Clarification: Community/home care nurses and other health care workers)
 - (i) Was this teaching helpful to you? Explain and give examples.
 - (ii) How would you assess the teaching you received? On what did you base your assessment?
- (i) What other learning resources did you have access to? (Clarification: people, literature, videos, etc...)
 - (i) Were these resources helpful to you? Explain and give examples.
 - (ii) How would you assess the information you received from these sources? On what did you base your assessment?
- (j) From your experience as a family caregiver, describe a situation in which you had to perform responsibilities or tasks that you felt that your teaching didn't prepare you enough for.

E1.3 - Interview protocol

Computer background

3) Computers and smartphones are still relatively new and some people are more used to them than others. I would like to ask you about your experience with computer technology

- (a) Please list everything you usually use computers or computer technology for in your daily life. Think of your daily routine if it helps.
- (b) Which computing platforms are you comfortable using? I'm talking about things like smartphones, tablets, personal computers...
- (c) How comfortable are you using those platforms?
- (d) Within the context of your role as a caregiver, what type of information do/did you typically look up on the internet?
- (e) Which websites do/did you use to look up this information?
- (f) How did finding this information affect your caregiving activities? Give examples.
- (g) Some people find that the information on the internet was insufficient, unclear, or hard to find, while others were very satisfied with it. What was *your* experience like? Give examples.
- (h) If a new application was to be designed to help caregivers such as yourself, what information would you like that app to contain?
 - (i) What features would you like it to have?
 - (ii) Think back on one situation in your caregiving experience where you needed help, and imagine having such an application at your disposal. Describe how you would use this application to solve your problem.

Conclusion

That about covers what *I* needed to ask you. What would *you* like to add? Do you think there is something that I should have asked you that I did not ask?

E2.1 - Nurses Focus Group protocol

Focus Group Introduction

Hello. I'd like to welcome you all and thank you for taking the time to be a part of this focus group. My name is Zeina Al Awar and I will be your moderator.

As I told you before, I'm conducting this focus group as a part of a research study that aims to develop a mobile application that would help family caregivers of cancer patients on palliative care learn how to perform their tasks properly in a home environment. As someone who has experience dealing with that group, I would really appreciate your professional input.

Now, some rules:

- We need everyone to participate, so I may call on you if you've been silent for a while.
- There are no right or wrong answers. You are all here because your opinions are valuable and your experiences are important. You're under no obligation to agree with everyone so I'd like you to share your opinions and stories even if you feel they are different.
- You have all signed the consent form and agreed to be audio recorded. I'd also like to remind you that the consent form included a confidentiality statement, so what is said in this room should stay here. Everyone will remain anonymous in our report and we won't identify anyone by name.
- You will not be required to breach patient confidentiality. I will ask you to share examples and anecdotes, but you should avoid mentioning the patient's or caregiver's name and all other identifying details.

E2.2 - Nurses Focus Group protocol

Questions

Alright, first question:

- 1- Please describe briefly your daily routine.
- 2- How familiar are you with my target population? (Clarification: Family caregivers of terminally ill cancer patients on home palliative care).
- 3- Please give examples of a situation where you had to deal with an overwhelmed caregiver.
- 4- In your experience, what topics do members of this population need to learn to be able to care for their sick family members more independently?
- 5- What methods of education have given you the best results? Give examples.
- 6- If a new application was to be designed to help family caregivers, what in your opinion should this app include?
- 7- Alright, that about covers what I needed to ask you. Does anyone have anything to add or think there is something else that I should have asked?

I'm going to go ahead and close this session. I'd like to thank you all. You were a tremendous help.

E3.1 - Informal Caregiver Focus Group protocol

Focus Group Introduction

Hello. I'd like to welcome you all and thank you for taking the time to be a part of this focus group. My name is Zeina Al Awar and I will be your moderator.

As I told you before, I'm conducting this focus group as a part of a research study that aims to develop a mobile application that would help family caregivers of cancer patients on comfort care learn how to perform their tasks properly in a home environment. As someone who's been in or is going through that role, I would really appreciate your input.

Now, some rules:

- We need everyone to participate, so I may call on you if you've been silent for a while.
- There are no right or wrong answers. You are all here because your opinions are valuable and your experiences are important. You're under no obligation to agree with everyone so I'd like you to share your opinions even if you feel they are different. You're also under no obligation to sugarcoat your opinion if it's negative. We appreciate politeness but we're looking for constructive criticism.
- You have all signed the consent form and agreed to be audio recorded. I won't be bringing up any sensitive information but I'd still like to remind you that the consent form included a confidentiality statement, so what is said in this room should stay here. Everyone will remain anonymous in our report and we won't identify anyone by name.

E3.2 - Informal Caregiver Focus Group protocol

Questions

Alright, first question:

- 1- Please describe briefly your duties as a caregiver.
- 2- What has happened here is that we have already conducted a series of interviews with caregivers such as yourselves, and used the findings from those interviews to extract a list of educational and informational needs that should be covered in the mobile application. I need to go over that list with you guys and I need you to give me feedback so I'd know if the list is accurate or if there was anything we missed or misinterpreted.
- 3- We also used the information from the interviews to design a mockup of what this mobile application should look like. I have printed some screen caps and I need you to look at them and give me your honest opinion. We will go through the steps you'd need to go through to use this application and you can tell me if anything feels wrong.
- 4- Do you think this application would be an effective method of supporting family caregivers such as yourselves? Why or why not?
- 5- Alright, that about covers what I needed to ask you. Does anyone have anything to add or think there is something else that I should have asked?

I'm going to go ahead and close this session. I'd like to thank you all. You were a tremendous help.

F1 - Less-Intense low-Need Caregiver

Daniel

“I like to talk to a voice, not a computer”

Background

- Lives with his wife of 36 years; 3 adult children have moved out.
- Graduated from high school, then worked in a number of manufacturing and transportation jobs before retiring 5 years ago.
- Enjoys daytrips, fishing, watching hockey matches, and playing online poker.

Attributes

- Cares for his wife, who is receiving chemotherapy for stage 3 ovarian cancer.
- Helps his wife move around and drives her to her medical appointments. Also responsible for all the housework, cooking, errands, and shopping.
- Does not think he *needs* information about his wife's illness but thinks he would feel better if he had it.
- Capable of using a computer and a smart phone to look up information, but not very comfortable doing it.
- Prefers to speak to a person to get explanations instead of having to read them online or on paper.

User needs

- Information about the nature of the illness, its progression, expected symptoms, treatments, and side effects.
- A simple way of learning about available resources, services, and programs.
- A simple and portable way to communicate with health care providers.
- Information presented in layman's terms.

Less-Intense Low-Need Caregiver (LILNC)

Personal profile

Mr. Daniel Hillard is a 68-year-old retired bus driver, living with his wife Miranda in a comfortable 2-story house in a small town a few hours from Ottawa. Last year, Miranda was diagnosed with stage 3 ovarian cancer, for which she had to undergo surgery and then start a course of chemotherapy.

Daniel and Miranda were very worried when they heard about the diagnosis. They asked their oncologist many questions about Miranda's chances of survival with the different treatment options he had suggested. Although satisfied with the explanation they received, they were still worried and curious, and promptly researched it on the Internet when they got home. They wanted to understand what ovarian cancer was and what it meant to be in a certain stage of cancer. They had also heard that chemotherapy was very unpleasant and wanted to learn what side effects to expect and what other women with ovarian cancer had experienced.

Daniel spent the past year helping Miranda and caring for her through one surgery and several courses of chemotherapy. As Miranda grew weaker, Daniel started preparing her meals and helping her move around the house, up the stairs, and to the washroom. Although their children sometimes visit and help out with the chores, it falls to Daniel to take care of the house and their general affairs, so he became responsible for the housework, errands, and grocery shopping.

Daniel and Miranda had a hard time navigating the health care system at first, and didn't understand the services available to them. They were referred to the CCAC by their GP and they are now visited on a weekly basis by a nurse who assesses Miranda's health status and follows up on her medications and her pain pump. A personal support worker also visits every other day to help Miranda bathe. When she's feeling better, they try to go out and visit friends or go to a restaurant.

After looking up the initial information, Daniel and Miranda didn't feel the need to research because they were able to ask their different doctors and nurses when they had questions, and they received satisfactory answers explained in simple layman's terms. Daniel isn't concerned about learning about the medications either, because Miranda is able to organize and take them on her own. Although he knows how to use a computer and owns a smart phone, Daniel isn't very comfortable doing Internet research and would prefer to speak to a person when he has a question. He would be interested in a mobile application if it made it easier for him to contact health care providers and speak to them directly.

Elaine

“I am absolutely amazed at the services that we have that we might not know about”

Background

- Lives with her husband of 14 years and their 10-year-old daughter.
- Graduated with a BA in English literature. Works as a copy editor.
- Enjoys reading, playing tennis, and spending time with her family.

Attributes

- Cares for her husband, who is on palliative treatment for recurrent stage 3 lung cancer.
- Helps her husband move around and manages his medication schedule. She is trying to adapt the house setup to accommodate his needs.
- Also takes care of the family's regular housework and errands.
- Comfortable with computer technology. Uses computers regularly for work and personal life. Owns an eBook reader and a smart phone.
- Only wants general information about her husband's illness, but would like more specific information about treatments and medications.
- Interested in learning about available resources and services, as well as sources of equipment and medical devices.

User needs

- Information about the nature of the illness, its progression, expected symptoms, treatments, and side effects.
- Information about medication management and administration.
- Information about mobility assistance, home alterations, and technical devices.
- A simple way of learning about available resources, services, and programs.
- A simple and portable way to communicate with health care providers.
- Information presented in layman's terms.

Medium-Intensity Low-Need Caregiver (MILNC)

Personal profile

Mrs. Elaine Benes is a 44-year-old copy editor who lives in Ottawa with her husband Jerry and their 10-year-old daughter Susan. Three years ago, Jerry underwent surgery to remove part of his right lung after being diagnosed with lung cancer. Four months ago, he was diagnosed with a recurrence of his lung cancer, which had also metastasized to his left lung, kidneys, liver, and adrenal glands. The family discussed the situation and decided to forego aggressive treatment and instead focus on spending more time together during Jerry's last year.

Elaine didn't know about any available services at the beginning, and had some trouble setting Jerry up at home after he was discharged from the hospital on oxygen therapy. After Jerry's oncologist referred them to palliative care, the process ran more smoothly. In addition to the occupational therapist consultation, Jerry is now visited by a personal support worker twice a week.

Since taking a Family Medical leave, Elaine spends most of her days now with Jerry. They read together in the family room or the back yard, and sometimes she drives him to his favourite diner for lunch. In the evenings they watch television with their daughter or play cards or board games, and on the weekends, they go out for picnics or take road trips.

In addition to being responsible for the housework, financial management, errands, and shopping, Elaine helps her husband move around, prepares his meals, and manages his medication schedule. She makes sure his oxygen tanks are always full and helps him go to the bathroom. Although he has a wheelchair, he prefers to use the walker whenever he can, and sometimes he walks with Elaine's assistance. Since getting up the stairs is becoming more difficult for him, she is planning to turn one of the downstairs rooms into a bedroom and to adapt the house setup to accommodate Jerry's needs with handrails and ramps.

Elaine had already researched lung cancer when Jerry had his first tumour a few years ago. She had read several books about cancer, cancer treatments, and cancer survival, in addition to online encyclopedia entries and multiple articles on cancer organization websites. She also visited patient forums to try to understand Jerry's experience better.

This time she is not interested in learning about the illness itself, but about treatments and medications that can make her husband more comfortable. Jerry doesn't feel much pain on a daily basis, but he is often tired, weak, and out of breath, and she wants to learn how she could help him. She would be interested in a mobile application if it included information about available resources and services, as well as sources of equipment and medical devices that she can use to make the house more accommodating to her husband.

Sean

“It’d be nice to have links, like to cancer information or palliative care or even as basic as a list of agencies that are available locally”

Background

- Lives with his elderly mother.
- Graduated from university with a degree in mechanical engineering, and has worked for a number of different airlines since.
- Enjoys camping, watching television, crossword puzzles, and pub quizzes.

Attributes

- Cares for his mother, who is suffering from stage 4 pancreatic cancer with bile duct obstruction.
- Reads to his mother, helps her move around, helps her adjust her position in bed, prepares her meals, and administers her medication.
- Works together with PSWs to meet his mother’s hygiene and toileting needs.
- Comfortable with computer technology. Uses computers regularly for work and owns a smart phone.
- Interested in learning about how his mother’s pre-existing illnesses affect her palliative medication regimen.
- Interested in learning about available health services and sources of medical equipment.

User needs

- Information about the nature of the illness, its progression, expected symptoms, treatments, and side effects.
- Information about terminal illness trajectories, the process of death and dying, and what to expect at different stages of decline.
- Information about medication management and administration.
- Information about mobility/positioning, home alterations, and technical devices.
- Information about assisting the patient with feeding, hygiene, and toileting.
- Information presented in layman’s terms.
- A simple way of learning about available resources, services, and programs.
- A simple and portable way to communicate with health care providers.

Medium-Intensity Intermediate-Need Caregiver (MIINC)

Personal profile

Mr. Sean Maguire is a 57-year-old engineer. He is single and lives in Ottawa in a small 2-bedroom house. For the past 12 years, Sean was helping his mother, Anna, care for his father, William, who was suffering from Alzheimer’s disease. Anna, who was already diabetic and asthmatic, was diagnosed with stage 4 pancreatic cancer shortly after William’s passing, and had to undergo surgery for bile duct obstruction. She became progressively more ill over the next few months until she was unable to care for herself, at which point she moved in with Sean and he became her caregiver.

Sean reads the newspaper to his mother and has family dinner with her every night. He prepares soft meals for her and makes sure that she swallows properly as she’s been choking more and more on her food lately. He also administers her medications and measures her blood sugar level twice a day. In addition to the personal support workers provided by the CCAC, Sean hired an independent PSW who stays with Anna while he’s at work.

For the first few months, Anna was moving around with a walker or with someone to lean on, but her progressive weakness soon made her unable to move around, and she now spends most of her time sitting in bed. Sean was able to purchase equipment to help with mobility and positioning, including a lift that helps get her out of bed and into a wheelchair, so that she can have dinner at the table. This has the added advantage of enabling her PSW to administer her daily bath in the washroom instead of in bed. Sean is planning to get her a hospital bed to make things even easier.

When Anna was referred to palliative care, the palliative doctor explained the different stages of functional decline to her and to Sean. Sean double checked most of the information online and was satisfied to find corroborating explanations. He especially valued the tables that outlined what to expect at each stage, and found that Anna’s condition has pretty much followed the same pattern. He now mostly looks up information about his mother’s symptoms and how to alleviate them, as he is worried that her pre-existing illnesses, especially diabetes, might affect her palliative medication regimen.

Sean has had some trouble obtaining the needed equipment for his mother, such as the oxygen generator and the lift. After bristling at the retail cost of some of the equipment, he managed to buy some of them second-hand and save thousands of dollars. However, he later found out, that some of these devices are available for rent at cheaper prices. He would be interested in an application that would present a simple but comprehensive picture of all available options for obtaining home medical devices and equipment, as well as paid and unpaid services available locally.

Christine

“If you could get that same information through your phone it would probably make things go faster”

Background

- Lives with her husband and 2 teenage sons.
- Graduated from high school and took a hairdressing course. Used to work as a hairdresser but had to take time off work to take care of her ill grandmother.
- Enjoys reading, gardening, going to restaurants, and family time.

Attributes

- Provides most of the care for her elderly grandmother, who is bedridden with metastatic liver cancer.
- Regularly relieved by her husband and children.
- Positions her grandmother in bed, provides her with pureed meals, and helps her with toileting and hygiene. Also manages her complicated medication regimen.
- Comfortable using a computer. Owns a tablet and a smart phone. Doesn't trust most of what she reads on the Internet.
- Interested in learning about the nature of cancer and how it metastasizes.
- Interested in learning about palliative care, nutrition, and different methods of medication administration.

User needs

- Information about the nature of the illness, its progression, expected symptoms, treatments, and side effects.
- Information about terminal illness trajectories, the process of death and dying, and what to expect at different stages of decline.
- Information about medication management and administration.
- Information about positioning, home alterations, and technical devices.
- Information about nutrition, feeding, maintaining hygiene, and toileting.
- Information presented in layman's terms.
- A simple way of learning about available resources, services, and programs.
- A simple and portable way to communicate with health care providers.

Medium-Intensity High-Need Caregiver (MIHNC)

Personal profile

Mrs. Christine Campbell is a 49-year-old hairdresser who lives with her husband of 23 years and their 2 teenage sons in a small suburb of Ottawa. Earlier this year, Christine's grandmother Mary became bedridden after her lung cancer metastasized to her liver, kidneys, endometrium, bones, and spinal chord.

When Mary and her oncologist decided to stop her treatment and focus on symptomatic relief, Christine offered to care for Mary at home in lieu of moving her to a hospice. Mary was happy to agree because she preferred to spend the remainder of her days with her family rather than moving to a new and unfamiliar environment.

Christine spends most of her days with Mary. She keeps her company and reads to her when Mary is not too tired. With the assistance of PSWs, she repositions her grandmother in her rented hospital bed, helps her maintain her hygiene, makes sure her oxygen therapy is working and her nasal cannula are clean, and provides her with pureed meals. While the CCAC does provide daily nursing visits, it is up to Christine to keep Mary on a complicated medication regimen, which includes administration of numerous pills and subcutaneous injections of morphine. Her husband Richard has tried to help by taking over all the errands, bills, and grocery shopping for the family, and her children added a lot of the housework to their regular chores. They also take turns sitting with Mary to give Christine time to rest, shower, or sleep.

When Mary was first diagnosed with cancer 2 years ago, Christine made sure to learn as much as she could about the disease online and from her friends who had gone through the experience before. She accompanied Mary to all her health appointments and asked the doctors and nurses everything she could think of. Christine now reads mostly about palliative care and pain control, and is trying to find out how she can prepare food that is easy to chew but won't trigger Mary's strong nausea.

Christine is comfortable using computer technology, but she distrusts the information found on the Internet, since "anyone can write anything on there." She tries to read information on the official websites of hospitals and health organizations, since she thinks they're more trustworthy. She received a lot of brochures and pamphlets from the many facilities Mary visited, dealing with topics like cancer and its complications, treatments, and side-effects, post-op care, palliative care, functional decline, home care, and pain management. She loves how succinct, comprehensive, and easy-to-understand they are and she would be interested in a mobile application that contains the same type of information but is easier to access and carry around.

Selina

“I need something resource-based, with information on the disease itself, key referral sources, things you could do as a non-medical professional, things you shouldn't do as a non-medical professional, and things you should be careful about”

Background

- Lives alone, but has been sleeping over at her mother's house for the last few months.
- Studied accounting and has worked in several federal agencies. Currently on extended family caregiver leave.
- Used to regularly volunteer at a hospice.
- Enjoys reading and knitting. Edits an art history blog.

Attributes

- Cares for her mother, whose status has been declining after being diagnosed with non-Hodgkin's lymphoma.
- Provides all of her mother's care, including feeding, positioning in bed, bathing and toileting, skin care, mouth care, and administering pain medication.
- Comfortable using a computer and a smart phone for most tasks.
- Wants to know everything about her mother's illness, with emphasis on its progression and what to expect next.
- Interested in learning about caregiving, especially things she can do to prevent complications of weakness and immobility.
- Interested in learning about the process of death and dying, and what will happen next during her mother's decline.

User needs

- Comprehensive information about the nature of the illness, its progression, expected symptoms, treatments, and side effects.
- Comprehensive information about terminal illness trajectories, the process of death and dying and what to expect at different stages of decline.
- Comprehensive information about palliative care and symptom management.
- Information about medication management and administration.
- Information about positioning, home alterations, and technical devices.
- Information about nutrition, feeding, maintaining hygiene, and toileting.
- Information presented in layman's terms.
- A simple way of learning about available resources, services, and programs.
- A simple and portable way to communicate with health care providers.

High-Intensity Caregiver (HIC)

Personal profile

Ms. Selina Meyer is a 48-year-old divorced federal employee with 2 adult sons who live in another province. Her 76-year-old mother, Catherine, was diagnosed with non-Hodgkin's Lymphoma six months ago. Catherine was previously starting to display increasing levels of forgetfulness in addition to having a history of arthritis and recurrent pneumonias.

Selina and Catherine spoke to the oncologist and looked up additional information online. Due to Catherine's age, her declining health, and the poor prognosis associated with her type of cancer, they decided to forego more aggressive treatments and focus on palliative options. Catherine didn't want to move out of her house, so Selina moved in to Catherine's spare bedroom to spend as much remaining time as possible with her mother.

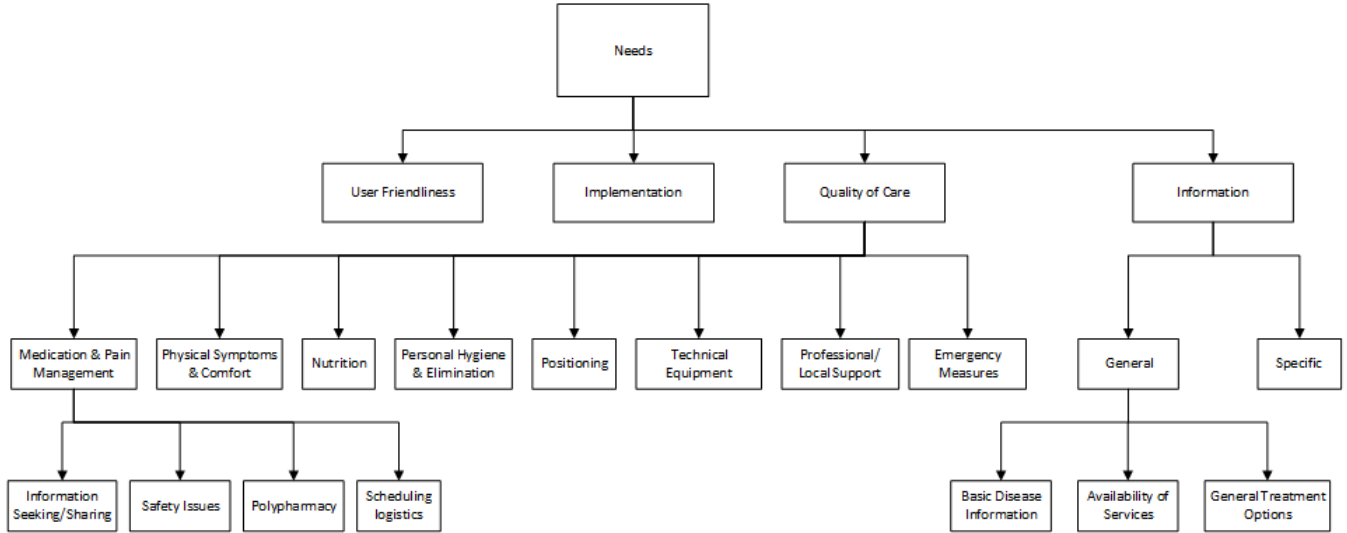
After taking a family caregiver leave, Selina now cares for her mother full time, relieved by a personal support worker who comes for a few hours each day. Catherine's status has been steadily declining, as she went from walking independently, to walking with assistance, to being completely bedridden. Her appetite declined significantly and she has become very weak and emaciated. She has also become increasingly drowsy, spending the majority of her days asleep.

Selina's activities changed as Catherine's needs changed. At first she was only keeping her company, managing her affairs, preparing her meals, and organizing her complicated medicine regimen. Now Selina bathes and toilets her mother and repositions her in bed regularly to prevent pressure sores. She doesn't need assistance to move Catherine since her weight loss has made her very light, but she has managed to rent a hospital bed which made it easier. She tries to feed her pureed food and formula, but is often unsuccessful due to Catherine's weakness and lack of appetite. Selina also administers her mother's medications, which include oral and subcutaneous pain medications. Due to Catherine's increasingly decreased consciousness level, Selina's worried that she might be missing signs of pain or that Catherine won't be able to tell her when she needs something.

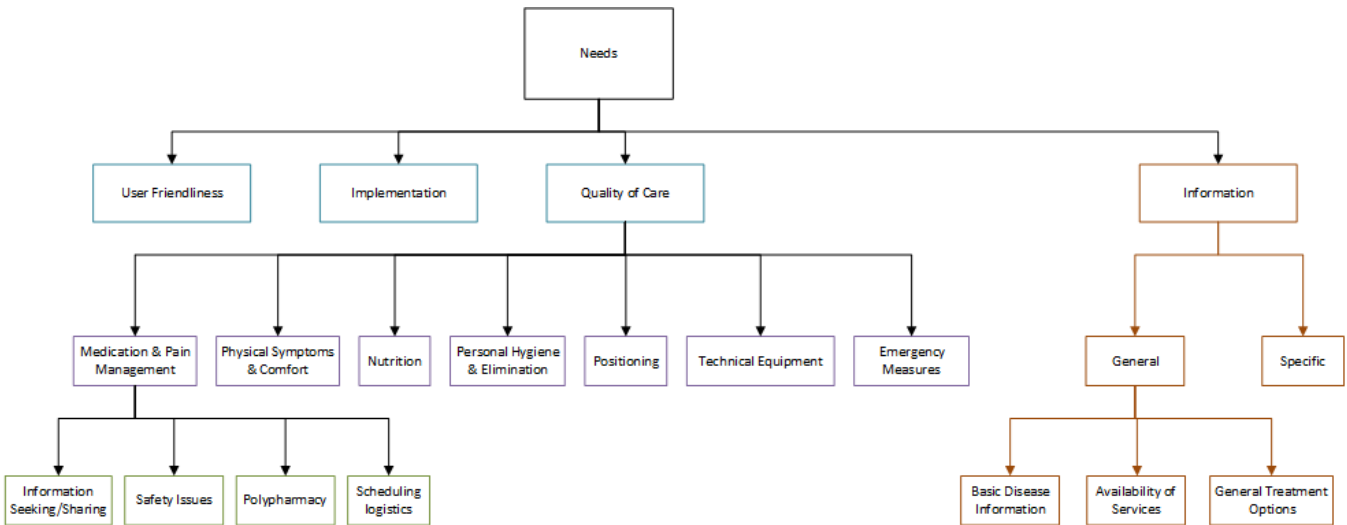
Selina spends most of her day on her laptop, usually reading about cancer, palliative care, and other issues relevant to her mother's care. She wants to learn everything she can about the situation, which she thinks can help her either with her care activities or to just alleviate her concerns. She likes websites of health organizations, like Cancer Care Ontario, but finds the information there too brief for her interests, which is why she visits many other sources of varying complexity, from medical journals to forums and personal blogs. She is mostly interested in learning about the trajectory of terminal illness and the process of dying, in order to anticipate the development in her mother's status, but she's had trouble finding this information due to the taboo nature of these topics. She would be interested in a mobile or web-based application that contains a checklist of all possible topics needed to care for her mother, including death and dying.

Appendix G: Coding Schemes

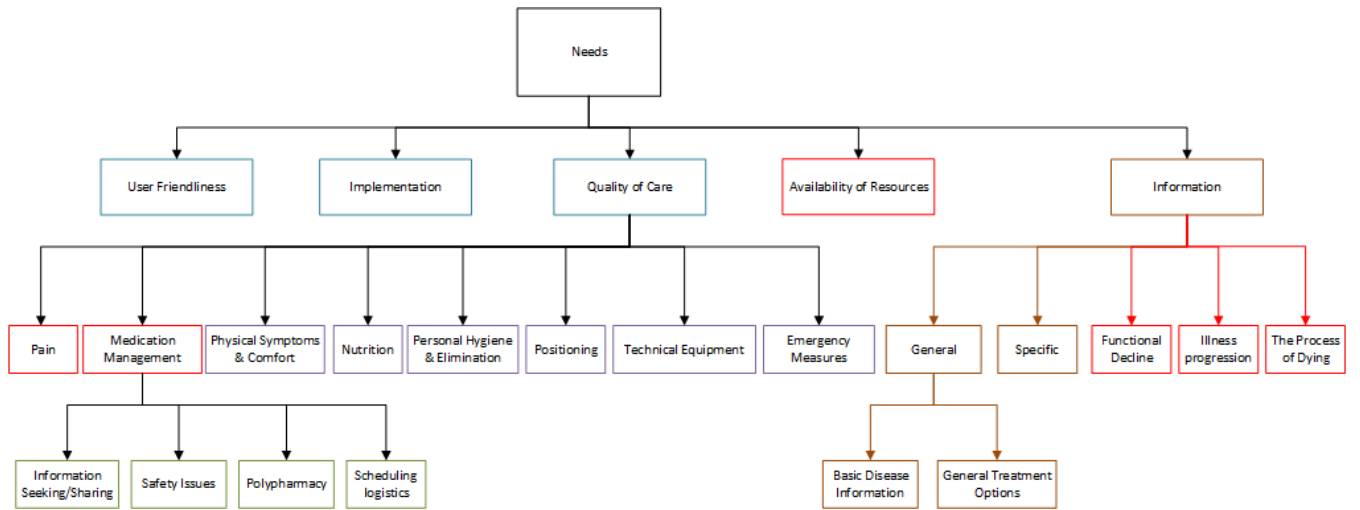
G1 - Coding Scheme 1



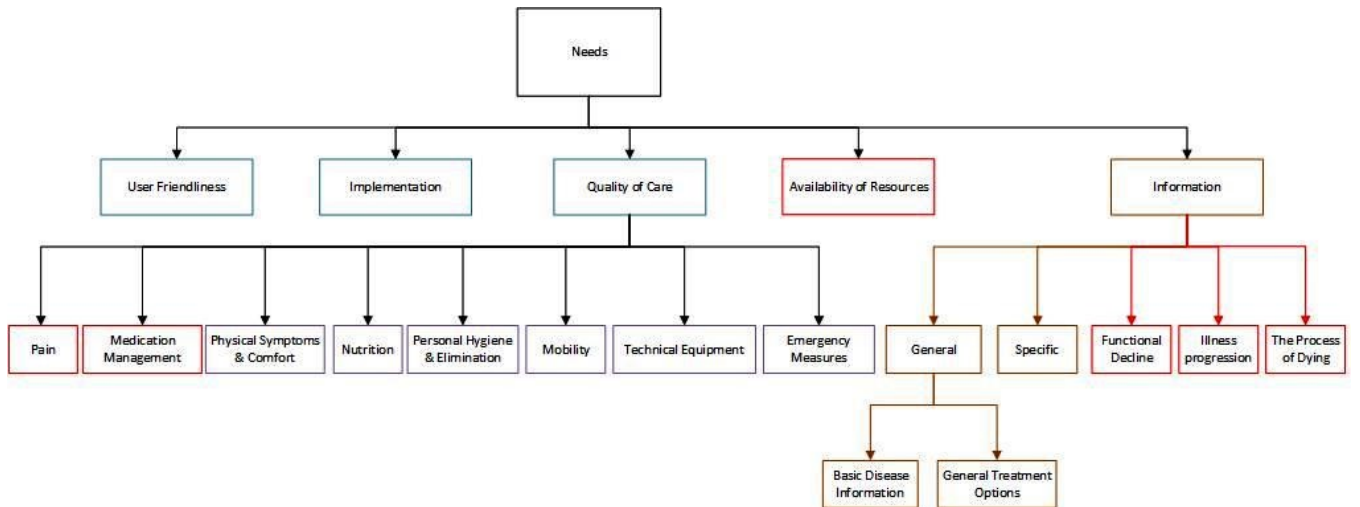
G2 - Coding Scheme 2



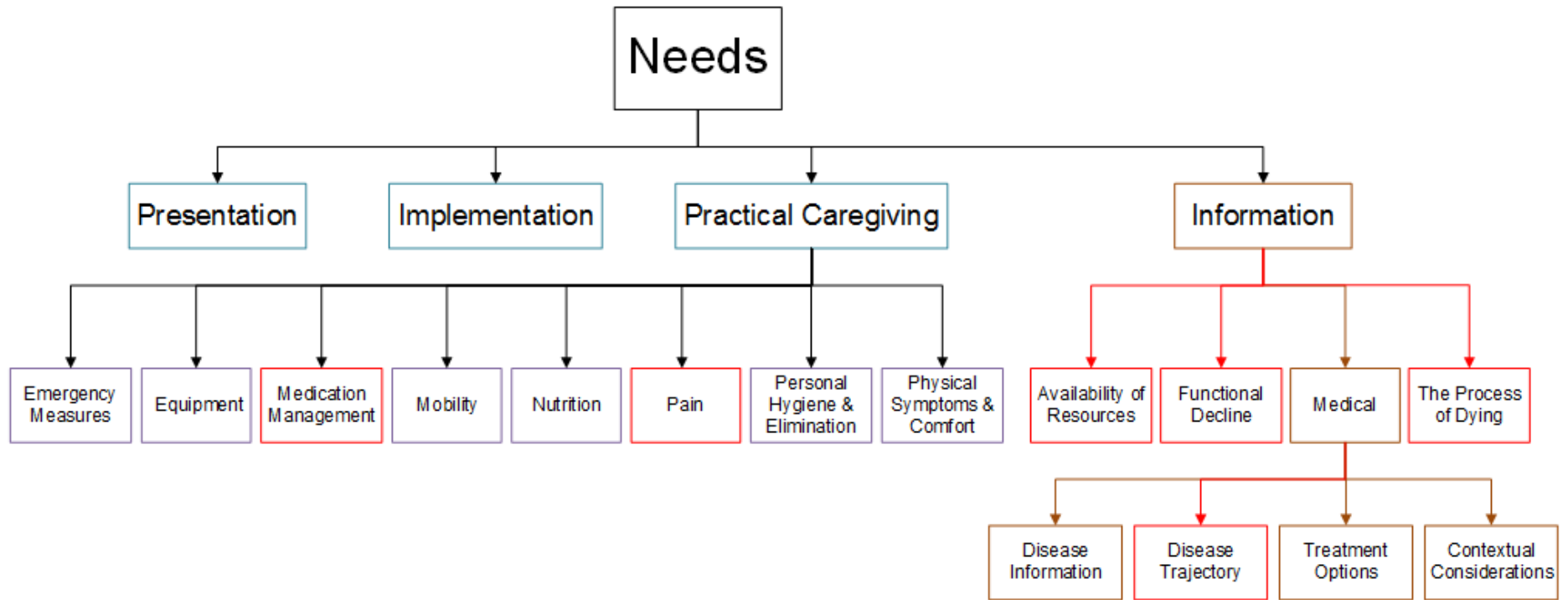
G3 - Coding Scheme 3



G4 - Coding Scheme 4

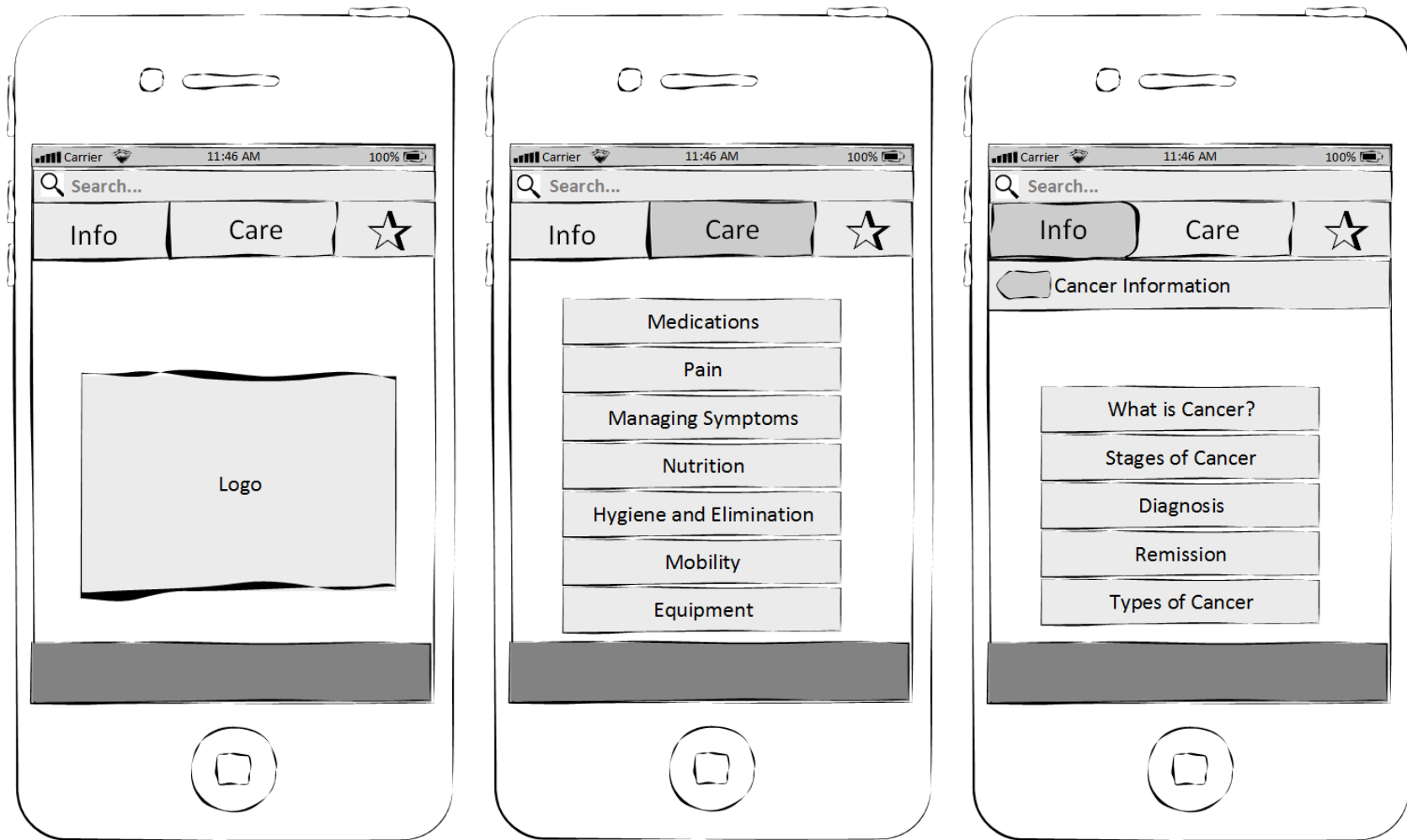


G5 - Hierarchical Structure of Informal Caregiver Needs



Appendix H: Low Fidelity Application Prototype

H1.1 - Low Fidelity Application Prototype version 1



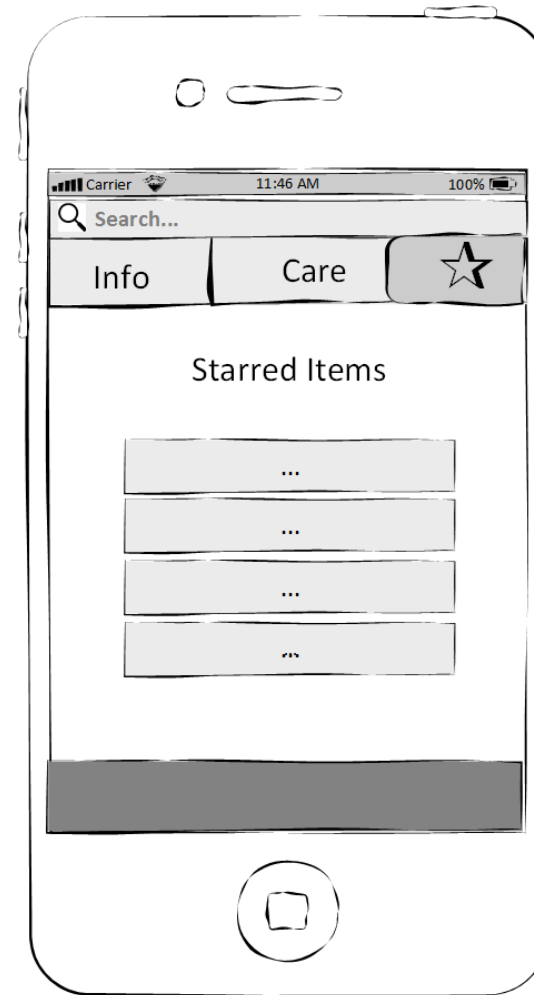
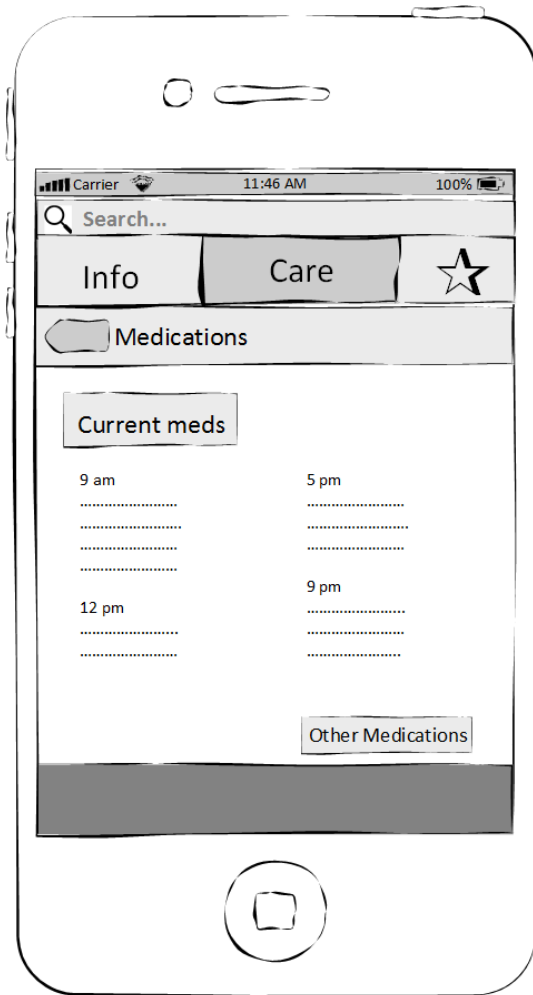
H1.2 - Low Fidelity Application Prototype version 1



H1.3 - Low Fidelity Application Prototype version 1

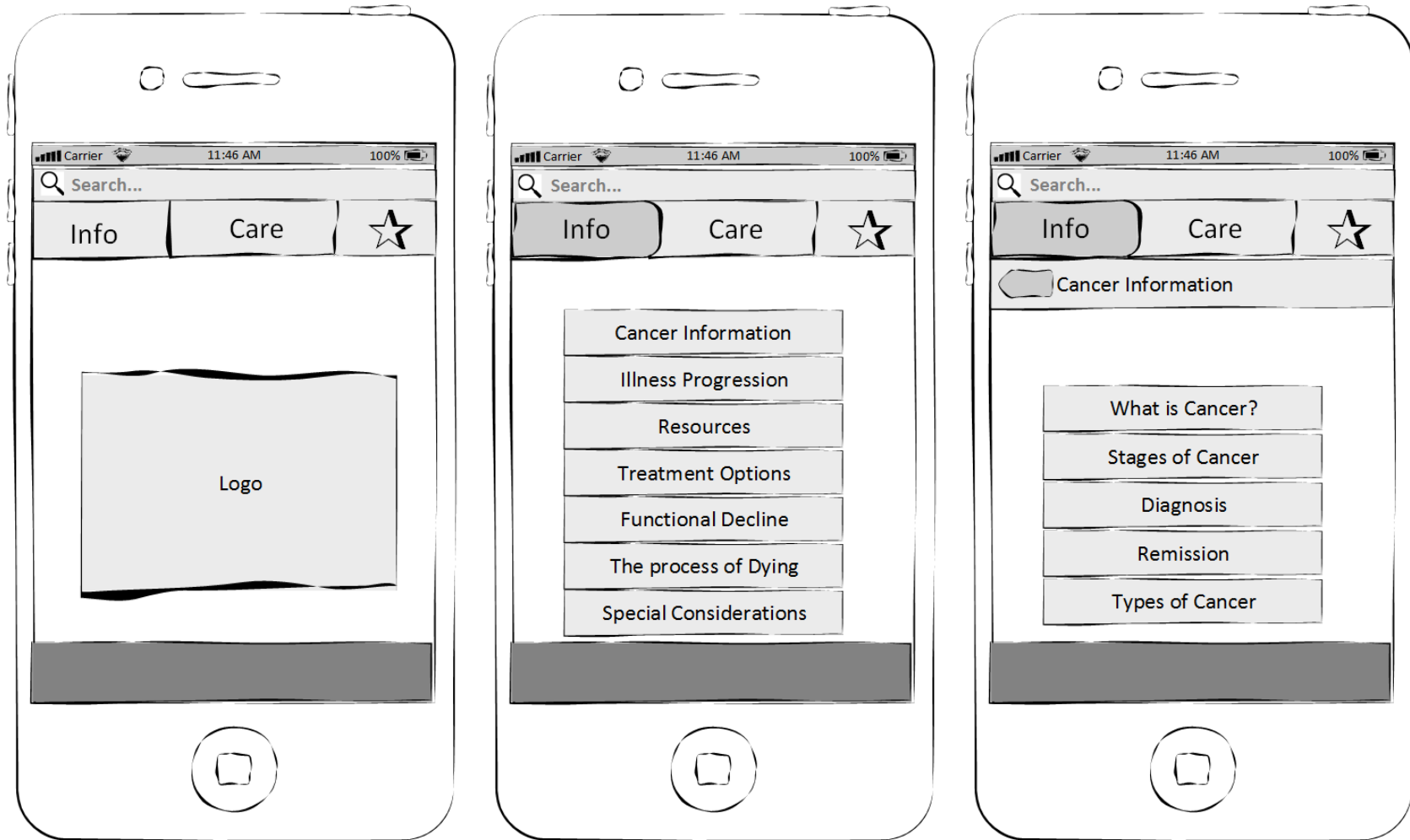


H1.4 - Low Fidelity Application Prototype version 1



H2: Low Fidelity Application Prototype Final Version

H2.1 - Low Fidelity Application Prototype final version



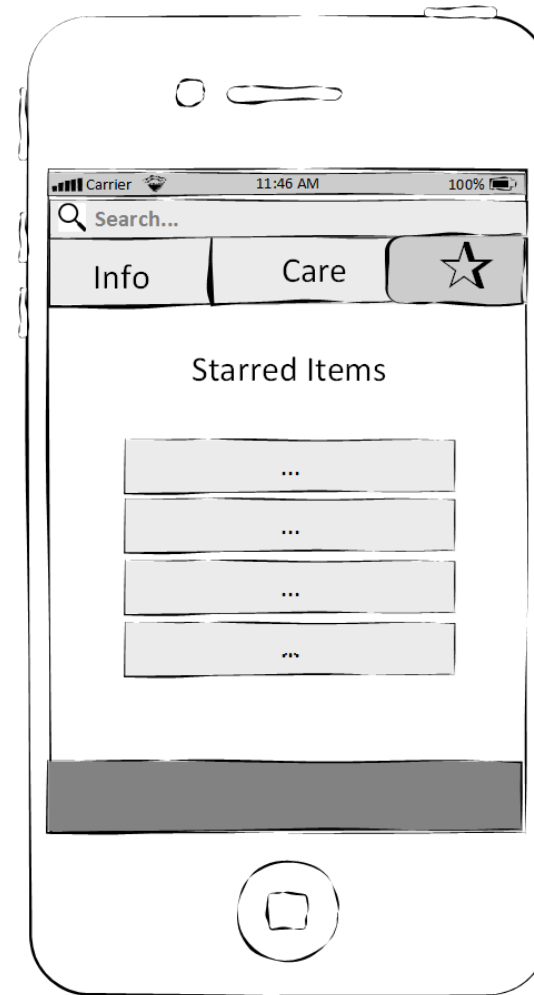
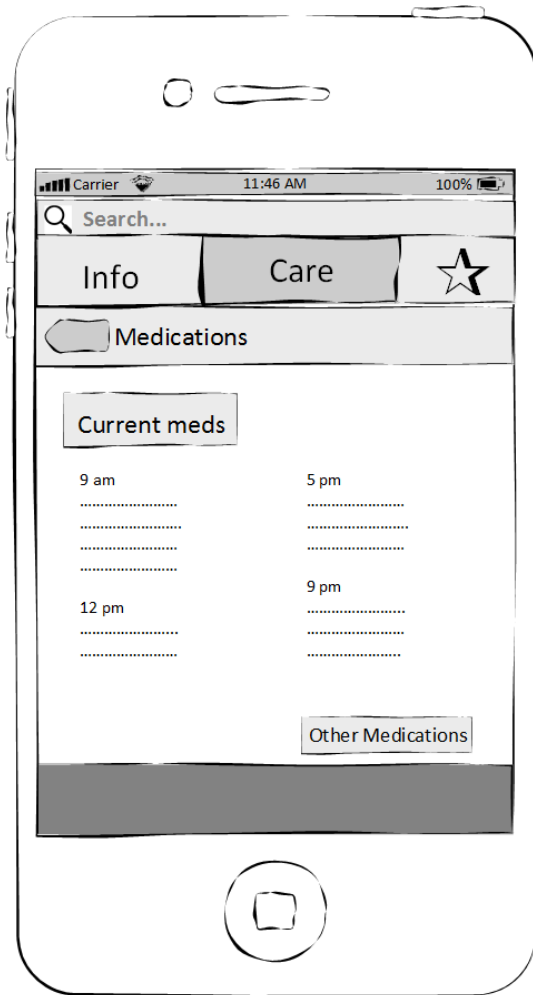
H2.2 - Low Fidelity Application Prototype final version



H2.3 - Low Fidelity Application Prototype final version



H2.4 - Low Fidelity Application Prototype final version



Appendix I: Initial Tables of Requirements

Table 8.1 Quality of Care		
Themes	Findings	Implications
Mobility Patient ambulation, lifting and handling, sorting pillows	-Mobility was the most common issue that arose in relation to practical caregiving, since this need arises even in patients with a high PPS score. -Informal caregivers of mobile patients often assist them with ambulation and caregivers of weak or bedridden patients need to reposition them in bed.	The application should contain instructions, diagrams, and videos (or links to videos) that illustrate how caregivers can help patients with their mobility. Assistance with all levels of functions should be included, such as walking, sitting, and other types of movements that a patient can actively participate in, as well as things that more passive patients need like lifting, turning in bed, and adjusting pillows.
	Informal caregivers of bedridden patients or patients with low level of mobility often have to deal with bed sores, contractures or other consequences of immobility	The application should list and explain the different consequences and complications of immobility. It should also include advice on how to prevent them and different methods of reducing or treating them.
	-Caregivers often modify the home environment to fit the patients' mobility needs and ensure their safety, such as installing rails and ramps or moving patients' bedrooms to more easily accessible locations. -Many caregivers have to deal with medical equipment that supports patients or helps lift or move them.	The applications should contain explanations of different types of home modifications that can be done to help patients carry on their activities of daily living as independently as possible. It should also include a description of mobility devices patients can use, such as canes, wheelchairs, walkers, etc... and heavier positioning equipment such as lifts and hospital beds that the caregiver can use to reposition the patient in bed.
Medication Management Medication awareness; subcutaneous drug administration skills, treatment of	Some participants were caring for patients who were able to manage their own medication regimens, but others had to handle the procurement, management, or even administration of the medications.	The application should include instructions on different methods of medication administration, including oral, topical, subcutaneous, inhalations, etc...
	Many participants were interested in reading about the different medications their patients were on,	The application should contain a specialized consumer drug guide that deals with common drug categories

Table 8.1 Quality of Care

Themes	Findings	Implications
side-effects; use of natural therapies	including chemotherapeutic drugs and drugs to control pain and nausea.	used by cancer patients, such as different chemotherapeutic agents, medications used to treat side effect, and other relevant products. The category, indications, dosage, methods of administration, side effects, and interactions with other drugs should be briefly explained in a simple language that non-medical professionals can understand.
	Cancer patients, especially those with chronic comorbidities like diabetes or kidney disease, often have very complicated medication protocols with multiple medications that are sometimes prescribed by different physicians.	The application should contain advice on the logistics of scheduling complicated medication regimens to ensure the optimal effects and avoid dangerous drug interactions. It should also touch upon managing refills for medications prescribed by different physicians. Ideally the application could contain a drug management tool that helps the caregiver log medication administration times, or orders drug refills.
Personal Hygiene and Elimination Bathing, cutting toe nails and dressing; bowel management; coping with incontinence; changing a catheter.	Some caregivers had to provide assistance to the patient with their hygiene and toileting. Some caregivers had to cooperate with PSWs to provide full care of the patients' hygiene, toileting, and grooming.	The application should contain descriptions of best ways of providing the patient with hygiene, grooming and toileting needs. Instructions and explanations on how to use and clean up after commodes, urinals, bedpans, catheters, and diapers should be included. Topics like bathing in bed, mouth care, eye care, and clipping nails should be explained as well. Ideally, suggestions on how to avoid complications like rashes and urinary tract infections should also be included.
Nutrition Provision of dietary advice; management of	Providing meals or feedings is one of the most major responsibilities of family caregivers. Additionally, family caregivers of cancer patients	The application should contain information about different dietary needs of cancer patients, and how these needs can be met. It should also discuss

Table 8.1 Quality of Care

Themes	Findings	Implications
weight or appetite loss; feeding techniques; prevention of dehydration	and palliative patients have to deal with special diets and different feeding techniques.	different methods and techniques of providing meals and feedings, depending on the patient’s individual needs. It could also include a description of different nutritional supplements and devices or tubes that could be used to administer them. The application should also inform caregivers about nutritional complications cancer patients are at risk of, such as malnutrition and dehydration, and how to deal with common symptoms and side effects that affect eating, like nausea and impaired swallowing.
Physical Symptoms and Comfort Management of weakness and fatigue, nausea and vomiting, mouth ulcers, oedema; wound and skin care; symptom recognition	-All participants expressed concern over the physical comfort of their patients. -Home care nurses stated that family caregivers usually ask many questions about dealing with nausea, fatigue, and other such symptoms.	The application should include a list of common symptoms that patients have to deal with, such as nausea and vomiting, mouth or skin sores and infections, shortness of breath, fatigue and weakness, edema, constipation or incontinence, confusion, drowsiness, etc... Each sign or symptom should be explained and its different treatments should be discussed. Ideally, the application should also include simple non-medical ways informal caregivers can treat symptoms and provide comfort, such as elevating the legs to decrease edema, and providing small quantities of bland food for nausea.
Pain Knowledge of pain types, assessment and management	-Concern over pain and pain management is a major concern of family caregivers. -Caregivers of patients with an impaired ability to communicate were worried that they might be unable to detect when their patients were in pain and thus leave their pain untreated.	The application should contain different ways of assessing pain, taking into consideration that patients could be at different levels of consciousness and communication. The application should provide explanations of the different types and classes of pain medications, with their side-effects, special considerations, and methods of administration.

Table 8.1 Quality of Care

Themes	Findings	Implications
	<p>-Home care nurses stated that pain management is one of the most common concerns of family caregivers of dying patients, and that poor pain management generates a lot of feelings of guilt or helplessness and often interferes with their coping with the situation.</p>	<p>The application should also discuss non-medical ways of treating pain and links to articles discussing pain and pain management in palliative care at length.</p>
<p>Equipment Awareness of availability, access, optimal positioning and use</p>	<p>-Many informal caregivers need to handle some medical devices or equipment at some point, such as walkers, wheelchairs, hospital beds, medication pumps, oxygen generators, and blood glucose meters.</p> <p>-Some informal caregivers have to handle medical tubes and supplies, such as catheters, feeding tubes, and wound dressings.</p> <p>Some participants had a hard time finding and acquiring medical equipment for use at home. Common problems were lack of awareness of suppliers and sources and financial costs.</p>	<p>The application should contain a brief explanation of the different types of medical equipment and supplies and their function.</p> <p>It should also include instructions for using the equipment in the relevant section according to function (eg: wheelchair in mobility section, feeding tubes in nutrition section).</p> <p>The application should contain a brief explanation about the usual methods of obtaining medical equipment, such as buying from a supplier, buying second hand, or renting, along with links to sources of such equipment.</p>
<p>Emergency Measures Recognizing signs of imminent death; knowledge of emergency measures and provision of emergency contacts</p>	<p>-Some participants had worrying experiences where they had to call an ambulance or a health care professional to deal with symptoms or incidents that were not part of the patient’s initial illness, such as the uncontrollable bleeding or the patient sustaining a fall.</p> <p>-Nurses indicated that some caregivers and even some health care professionals are unsure of the extent patients with a DNR should be treated in an emergency situation.</p>	<p>The application should include instructions on what to do in case of different emergency situations. It should details situations which could be dealt with by the caregiver and others where help should immediately be sought.</p> <p>Ideally this application should also contain information about the scope of palliative care and what can be done for a DNR patient in cases of unanticipated deterioration or non-life threatening injuries.</p>

Table 8.2 Educational Needs

Themes	Findings	Implications
<p>Process of Dying Inductive. Anything related to the process of dying, including the decline in the patient's health and functional status, and the first stages of the caregiver's bereavement.</p>	<p>Most caregivers are interested in learning about the signs of an impending death so they can know what to expect to happen.</p>	<p>The application should contain a brief description of the different stages of the process of dying, including the signs and symptoms of an impending death and the changes that happen to a person's body when they pass away. Ideally, the application would also provide links to articles that discuss the subject in depth</p>
	<p>Some people are unfamiliar with the legal and practical issues that needs to be dealt with following a person's death.</p>	<p>The application should contain a brief list of details to be taken into consideration when a death is expected or after it occurs. This could include making a last will and testament, posting an obituary, making funeral arrangements, obtaining a medical certificate of death, etc...</p>
	<p>Informal caregivers of palliative patients often have a hard time facing the impending death of their loved one and have start the process of bereavement earlier than usual.</p>	<p>The application should include information about the different stages of bereavement and possible methods of coping. It should also contain links to local resources, programs, and support groups that deal with bereavement.</p>
<p>Basic Disease Information Information about Etiology, diagnosis, and general prognosis</p>	<p>Most participants were interested in learning about cancer, how cancer occurs, its symptoms, and what the different stages of cancer mean. They are also very interested in prognosis and how prognosis is measured.</p>	<p>The application should include a general explanation of what cancer is and how it occurs, along with more specialized descriptions of different aspects of cancer and pertinent details. Ideally the application will include:</p> <ul style="list-style-type: none"> • A section that explains the types of cancer organized by cell type. • A section that explains metastasis and the different stages of cancer. • A section that explains different diagnostic procedures for different types of cancer. • A section that explains remission and methods of measuring prognostic factors.

Table 8.2 Educational Needs

Themes	Findings	Implications
		<ul style="list-style-type: none"> An alphabetic list of different types of cancer classified according to their location, with a separate section for each item on the list detailing the etiology, risk factors, signs and symptoms, diagnostic procedures, and prognostic considerations. <p>Each section should be brief but comprehensive and contain links to information resources that caregivers can peruse if they wanted more detailed information.</p>
<p>Illness Progression Inductive. The various complications the patient goes through as the disease itself becomes more vicious.</p>	<p>Participants were interested in learning about what they and their patient should expect from the cancer, including things like progressive worsening of cancer symptoms, and what complications could result from the cancer or its treatments.</p>	<p>The application should contain information about complications or advanced cancer or cancer treatments, and the signs and symptoms that accompany those complications.</p>
	<p>Many caregivers were unclear about what metastasis is, how it can occur, and which organs it can affect.</p>	<p>The application should explain the concept of metastasis and its etiology and its usual patterns.</p>
	<p>Participants wanted to learn how remission is determined, and what the chances of recurrence were for different types of cancer.</p>	<p>The application should include a section that explains how remission is determined and what factors can influence it for different types of cancer. It should also explain recurrence, its treatment options, and how it differs from progression.</p>
<p>General Treatment Options Different options available for treatment of patients, and the likely</p>	<p>Participants wanted to know about the different treatments available for their patients were, and how effective each option was likely to be.</p>	<p>The application should contain information and explanations about the most common treatments for the different types of cancer, the difference between them, and how effective they have proven to be in different scenarios. There should also be links to more advanced information, such as different chemotherapy protocols.</p>

Table 8.2 Educational Needs

Themes	Findings	Implications
effects and side-effects of each treatments.	Many of the symptoms cancer patients and their family caregivers have to deal with are side effects of chemotherapy, radiation, surgery, or other treatments.	The application should include information about common side effects of cancer treatments, with more in-depth explanations of the most common effects and different ways they are generally treated or dealt with.
	Nurses often have to deal with caregivers and others who are unsure of what palliative care entails and what its scope is.	The application should provide explanations of what palliative care is, what it entails, what it aims to do, and what are its limits. Ideally, this will also contain an emphasis on how palliative care and curative care are different approaches that are nevertheless compatible with each other.
Functional Decline Inductive. The gradual reduction in the patient’s physical and cognitive functioning, which leaves the patient requiring assistance in performing increasingly basic activities of daily living.	-Most of the responsibilities of the participants revolved around compensating for functions that their patients had lost, such as independent mobility or the ability to manage their own medication protocol. -Patients’ functional decline often caused a lot of stress for both the patients and their caregivers	The application should contain explanations of functional decline, why it occurs, and the patterns it usually follows. It should also contain explanations about the different ways of measuring functional decline, such as the Palliative Performance Scale or the Karnofsky Scale, and methods of dealing with functional decline or slowing it down.
Contextual Information Information tailored to individual caregiver needs	Each cancer patient has their own unique circumstances that their condition will be governed by, which means their caregivers would have to learn about topics that are unique to that case and not shared by other caregivers.	The application should contain sections that briefly discuss special circumstances, such as common comorbidities. It should also include things like rare conditions, treatments and complications that not all patients go through but would be very important to the caregivers of those who do.

Table 8.2 Educational Needs

Themes	Findings	Implications
		<p>Since not everything can be covered in the application, there should be links to topics that are rare or too specific.</p>
<p>Availability of Resources Professional or local support, Access to night services or 24-hour support; signposting to local resources and/or agency help. Information about programs providing financial guidance and support.</p>	<p>-Obtaining, recording, and managing contact information of different health care professionals or organizations is one of the major roles of informal caregivers. -Some caregivers have a hard time learning about different resources are available to them.</p> <p>Many caregivers prefer to speak directly to someone who can help or provide explanation.</p>	<p>The application should provide a directory that caregivers can use to find contact information of all services, programs, and other resources available to them.</p> <p>It would also be a good idea for the application to contain a way users can access their most frequently used contact details quickly instead of having to look in the directory every time they needed them. This could be done by creating a list of favorites where contacts from the directory can be added. This list should be available on a separate screen for quick access.</p> <p>The application should provide a method of communication between the informal caregiver and the health care system.</p> <p>Ideally, the caregiver would be able call health care professionals, or representatives of their health care system, directly from their mobile application. Other options, such as communicating with health professionals via short text messages or even links to a nursing hotline could also be useful.</p> <p>The implementation of this feature would depend on the specific health care system and its available services, but it could be something as simple as redirecting the user to the general inquiries number of the Community Care Access Centre of their Local Health Integration Network.</p>

Themes	Findings	Implications
	Some caregivers want to know about all resources available to them, even those they have to pay for themselves.	The application should provide information about all services available to the caregiver, even those not covered by their provincial health plan. Ideally, services could be separated according to methods of payment, into “completely subsidized” “partially subsidized” and “paid” categories.
	Participants wanted to know about services directed towards caregivers, such as counselling, support groups, and other things that could help them care for themselves.	The application should include links to local programs directed towards informal caregivers, such as support groups and workshops. Ideally, it should also contain a section that provides brief instructions on how to avoid caregiver burnout.
	Many participants mistrust what they read on the Internet and prefer information found on official-looking websites that they feel are more trustworthy.	Each section of the application should provide succinct information, with links to resources that would enable the caregivers to read further about the subject. The resources would likely be trusted implicitly by the caregivers since they would be provided by a proxy of the health care system, so the developers of the application should make sure to link to trustworthy sources that provide updated and evidence-based information.

Themes	Findings	Implications
User Friendliness Technical and Usability issues	-Participants desire something easy to access and transport -Most participants were adept at using a personal computer to look up information.	The application should be either a mobile (smart phone or tablet) application or a web-based application. Ideally, it could be a web-based application that could be accessed via a web interface, mobile web, and a mobile application.
	Ottawa is a bilingual city, and like most big cities in Canada, it is	The application should be available in multiple languages

Table 8.3 User Friendliness

Themes	Findings	Implications
	<p>highly diverse and houses people of different backgrounds and cultures. Home care nurses often have to resort to crude or unverified web translations to communicate their teaching to family caregivers.</p>	<p>Ideally, it could first be developed in English and French, and then more languages can be included based on the frequencies of different languages in the population of the local area in question.</p>
	<ul style="list-style-type: none"> -Caregivers actively seek information on the web that is easier to understand. -Some caregivers attempted to read difficult medical material, such as research articles and MRI reports. -Caregivers identified “using layman’s terms” as one of the qualities of a good application, as well as the main reason for liking the explanations or written material provided by some health professionals. -Some nurses recommended applications and websites designed for health professionals to caregivers, because they were written in a relatively simple language. 	<p>The application should use very simple language, which avoids most technical terms and medical jargon. It should be written for a 6th to 7th grade reading comprehension level, according to the guidelines of Medline Plus’ <i>How to Write Easy-to-Read Health Materials</i>”</p>
	<p>Different informal caregivers preferred different methods of education, including reading articles, browsing leaflets and brochure, talking directly to ask health care professionals, watching demonstrations, and looking at diagrams and other visual representations.</p>	<p>The application should include information presented in different ways. It should include brief written material and diagrams/illustrations, but should also include links to more in-depth articles and videos.</p>
	<p>Caregivers desire concrete information about tangible changes to the patient’s condition that they can observe or measure.</p>	<p>The application should include concrete information such as lists of symptoms presented in the order they are expected to occur.</p>

Appendix J: Caregiver Needs with Relevant Quotes

Table 9: Caregiver Needs with Relevant Quotes			
Needs		Quote	
Presentation		I don't believe that there's any one way of doing it. I mean each individual is a different type of learner. Some people learn better by reading, some people with hands on. Everybody has their own way.	NFG member
		... not only would the app have to deal with different languages but you'd have to remember that there's not always the education level there, so simple terms in some instances would be better than a terminology that we would understand.	NFG member
		I don't think they actually had a checklist. It was more sort of ad-hoc. Which is again another reason why an app would be useful. Because you have to think of what to ask them ... So a little checklist of what to ask a professional would be probably helpful	ICII01
		...when the nurses came I would ask them to do it and then I would watch. And I noticed that there were 3 different ways of how they did it. So I was confused but I found that the most important thing is the liquid, the distilled water, has to go through...	ICII02
		The doctors would give me the copies of the scans, and although it was somewhat above me. Above my knowledge, I understood most of it. It just gave me a better idea of what what going on and the progression of the cancer.	ICII06
		You can't always believe what you read on the Internet but it was readily available and provided quick answers...	ICII07
Information	Availability of Resources	We can consult social work. We can consult psych. We will direct them to those who are going to be of the most benefit to them.... All of us in here are very experienced at dealing with all of these situations, but there comes a time when their issues go far beyond the scope of our expertise, so we will then refer them to agencies, to individuals, psychologists, to social workers	NFG member
		Sometimes that's as simple as giving respite... I see one lady now and her husband is hitting burnout... So to keep this situation and patient at home I'll move mountains to get that 8 hours for him to get out and relax.	NFG member
		I knew basically nothing about how you interface with health services or what their role is or how you deal with them	ICII01

Table 9: Caregiver Needs with Relevant Quotes

Needs		Quote	
		We were trying to get ... the cancer drug. They were giving it to her at the hospital but they only had 2 days left...So I started phoning around to pharmacies in [TOWN] and I got one, and he asked me if I had a P card. Now that's a special card that you get which will cover your expenses...	ICII03
		She took 6 chemo treatments over the course of the winter. 3 weeks apart. We had to go back and forth to [CITY] for that.	ICII04
		You would know who to contact. The limits of what kind of care you could ask for or expect. Because there's all different rules right?... Like there's a time to find out how soon, once you're approved, you could expect the care to provide you help in your home.	ICII06
		I know there's a phone number in Ontario that is answered by nurses, that if you had an issue, that they could comment on and they could provide help over the phone. I suppose something like that would be good for personal support workers too.	ICII07
		... you should have all the contact information for the services in your area. The ones that you pay for. The ones that are free. The ones that are nurse care. The ones that are for home care. Even if it is to help them clean their house, because not everyone is married. Some people are by themselves...	ICII08
Functional Decline		she was resting a lot... by then she was not really interested in getting out of bed, I think she was getting so weak she had Cachexia. She was very wasted away. So I would go down and get breakfast in the morning. She would have it in bed...	ICII01
		...at the beginning [his children] were able to feed him themselves because he was able to hold a cup and drink from it, and over time then he used their strength so they could just hold it.	ICII02
		We'd still go out, when she was able and not tired. To different houses while she was able to go. And near the end of course she wasn't...	ICII03
		...we could see she was going down. She didn't want to get out of bed anymore. She didn't want to eat. She kept saying she wasn't hungry.	ICII05

Table 9: Caregiver Needs with Relevant Quotes

Needs		Quote	
		she was quite mobile... and like I said it was only about the last week or two that she needed more and more help and then she wasn't confined to her bed at all until the last 3 or 4 days.	ICII06
		Well I saw that she's pretty much followed the [functional decline] pattern. She was incontinent for a while and then she lost her ability to walk and she's bedridden. She sleeps about 23 out of 24 hours a day.	ICII07
	Medical: Disease Information	Certainly I wanted to know all about pancreatic cancer. And what are they symptoms of pancreatic cancer. And the complications and what should I be aware of ...	ICII01
		And they explained the type of cancer, and after the third operation when she started going downhill there was a slight change in the nature of the cancer. Beforehand it was spreading out laterally so to speak... The initial one was about the size of a loonie... And it started spreading out along the perimeter, the circumference. But the final one was fingers of the cancer going deeper into her brain. That was the difference in that type at that time.	ICII03
		everything from all the terminology, the cancer terminology, all the names of the organizations that helped us look after him. All the parts of the body, ...what was dangerous and what was just the norm for what he was at that time. And also knowing how it was going to progress because you need to know that. You need to prepare yourself for what's coming up.	ICII08
		[I wanted to know] mainly what is the condition. What's the condition of the person that you're trying to help. And it's got nothing to do with how they got there, it's like what are you going to do now to help them? So it's going to be mainly telling you what could happen when they have this and how would you go about supporting them.	ICII08

Table 9: Caregiver Needs with Relevant Quotes

Needs		Quote	
	Medical: Disease Trajectory	That's really something that's part of our job. I will spend a lot of time with the family if someone is at a PPS of 20, 30 and is heading south, and say "okay, this is what's happening. This is how the body's going to shut down. So when you touch the hand or the feet and it's cold that's normal. It might dissipate or it might stay that way. This is the next thing that's going to happen, this is why we need to know if there's congestion. We need to give this medication, or we need to do this". So you spend a lot of time explaining and teaching the family so that when it does happen, ... they say "you were right. It happened and it went away. I wasn't frightened because I knew what to expect".	NFG member
		I learned a lot about pancreatic cancer and stages of pancreatic cancer and the prognosis which is pretty terrible, and how long it usually takes to die.	ICII01
		Well, we wanted to know what the stages of cancer and what her chances of survival are and all that stuff.	ICII04
		I didn't know that colon cancer can spread to your lungs, liver, heart. I knew it could spread but I didn't think it would spread that high.	ICII05
		The doctors would give me the copies of the scans, and although it was somewhat above me. Above my knowledge. But I understood most of it. It just gave me a better idea of what going on and the progression of the cancer. And her family doctor was very helpful... And he was frank, and very forthcoming with his expectations or limitation on what was going to happen...	ICII06
		And also knowing how it was going to progress because you need to know that. You need to prepare yourself for what's coming up.	ICII08
	Medical: Treatment Options	There's a difference between active treatment and palliative treatment. You can do palliative treatments to control pain, to control swelling, other things like that. But if they're still seeking active curative treatment it's difficult for palliative doctor to go in and be successful because they're on completely different pages.	NFG member
		I did not have any need to read about cancer while I was taking care of him because at that point I knew that it was terminal...	ICII02

Table 9: Caregiver Needs with Relevant Quotes

Needs		Quote	
		In the second year we kept going with the chemo and we got to a point where we had it pretty well down what to eat prior to its start. She'd be on it for 5 days, eat the first night, and with all the anti-nausea pills she was taking, from the initial one after she got home after the first operation where she threw up 7 or 8 times a night, we were down to once or sometimes not even throwing up at all. She lost her hair when she was doing the radiation...	ICII03
		we found out that the cancer was spreading and talked it over with the oncologist and he thought that we had to make a decision. (voice shakes) Try again which might increase her life, he said, 2 or 3 months, with more of a handicap...	ICII03
		They told us what to watch for. For side effects and all this stuff. But she came through it pretty good. There wasn't a whole lot of side effects. I mean the first couple of treatments, that's normal. We knew what to expect. But other than that she came through it pretty good.	ICII04
		They put [the venous port] for the chemo. But when she stopped the chemo that device was still inside of her so they showed me how to put the needle into that device through a tube and then give her the morphine that way.	ICII05
		...they try to explain to you everything that could happen, what's going to happen, what the treatments would involve, what were her chances of accomplishing anything with treatments, what's the side effects.	ICII06
		[I want to know] the different options for someone who's in the state he was in. What could possibly make them comfortable...	ICII08
	Medical: Contextual Considerati on	The thing that I had to watch, now that you're asking, is the catheter. To flush it. To be able to put distilled water through it and to flush it and I did that every 2 days. And I was shown and trained how to do it. But not to change it of course it's only changed by the nurses.	ICII02
		She had diabetes for the last 20 years. Insulin Dependent.	ICII07

Table 9: Caregiver Needs with Relevant Quotes

Needs	Quote		
Process of Dying		That’s really something that’s part of our job. I will spend a lot of time with the family if someone is at a PPS of 20, 30 and is heading south, and say “okay, this is what’s happening. This is how the body’s going to shut down. So when you touch the hand or the feet and it’s cold that’s normal. It might dissipate or it might stay that way..., I’ve gone back and they say “you were right. It happened and it went away. I wasn’t frightened because I knew what to expect...”	NFG member
		it’s the fear of the unknown that is the most terrifying... If you’ve taken the time to sort of forewarn them that this is a very natural process and this is what you can expect to see, it alleviates the anxiety a hundred percent. They’re still gonna have other things to be anxious about, but in terms of the process of dying, we can’t control the process of dying but we can control the symptoms that are caused by it...	NFG member
		[I need information] on dying too. There's not real good place to actually find out if you want to really understand what are the real phases of dying. Because you do want to know that. Especially if you're a primary caregiver you want to know "can I go out for 2 hours or is..." I had a better knowledge because I've seen half a dozen people die, but if it's your first person that you've been around, you wanna know "Can I sleep for a few hours? Is my mother...?"	ICII01
		We both knew what was going to happen. And we understood the drugs and, you know, the decline.	ICII03
		[I used] palliative care brochures to read on that. Brochures on the colon cancer. Brochures for death at home, you know, preparing for death at home	ICII05
		Her family doctor was very helpful... And he was frank, and very forthcoming with his expectations or limitation on what was going to happen and right from the start she had a do not resuscitate and that puts doctors and hospitals all in the same light so that they know what her requests were.	ICII06

Table 9: Caregiver Needs with Relevant Quotes

Needs		Quote	
		The palliative care doctor did [explain]. The stages of dying, the loss of mobility, the loss of appetite, the loss of willingness to swallow, the difficulty breathing... And then the trying to make them comfortable and the passing away.	ICII07
		[What an app needs to include] "if this is the type of illness and this is the stage they're at. And yes it's terminal and yes they'll go into palliative care. This is what you could expect. What you should expect"	ICII08
Practical Caregiving	Emergency Measures	...if they fall and break their arm or break their hip we're not going to leave them lying in that pain because they're palliative. We're going to send them for the treatment to get a cast or get whatever...	NFG member
		I guess I just dealt with it and within a few hours, we had called an ambulance for her to go, because her fever had progressed and it was another bout of pneumonia.	ICII06
		Well the nose bleeding. That freaked me out. Because I went to see him and he's got Kleenexes full of blood and I said to him "My god! How long has it been like that?" "Oh, over an hour" And then I took it and it was just pouring out and I said let's just put a pressure on it. It took a good half hour for it to stop gushing out but it eventually stopped and we called the doctor next day... they [cauterized] one of the veins in his nose... but yeah that freaked me out.	ICII08
	Equipment	So I would go down and get breakfast in the morning. She would have it in bed because we were able to get a hospital bed moved in there [and] one of the tables that goes over the bed, so she could feed herself.	ICII01

Table 9: Caregiver Needs with Relevant Quotes

Needs	Quote	
	<p>I guess just a simple thing is equipment... How could you get a hospital bed if you needed one. If you're looking after somebody that you know is going to die you're not going to go out and buy a hospital bed... I didn't really know what I could get that would make her most comfortable, so I never might actually have thought of a hospital bed. Because you think "well she's in her own bed she'll be comfortable there," but then somebody suggested "well it would be nice if she can sit up because it helps her breathing." And I said you know the hospital beds are 2 or 3 thousand dollars, so if the app was there I would have gone on the app and said "what things could I consider to make my family member more comfortable?" And then it would say "think about this or that? And these are possible sources..."</p>	ICII01
	<p>I didn't have information as to where to go, what would I do if he was not able to walk? And so I googled devices to use. Like where do I get a wheelchair, and how? Am I buying? Am I renting? So I phoned 3 different places. But then I decided to talk to my sister in law ... So she has contacts and they suggested the red cross. And that's how we got our first walker from the red cross.</p>	ICII02
	<p>The last month we moved downstairs. CCAC said when you need a bed it'll be there for you. We also had a transport chair for [WIFE] because she couldn't walk long distances. And we had also a full wheelchair. [COMPANY NAME] up at [TOWN] provided that. For longer halls and rougher things. But then eventually she deteriorated and we needed a hospital bed.</p>	ICII03
	<p>They brought up a person from [NURSING AGENCY] to teach us how to use the sling. And the color codes and so forth. How to use that. Again, I bought the lift off Kijiji because the one from the [MEDICAL SUPPLY COMPANY], they wanted an arm and a leg for it. Like it was \$2000. I bought pretty much the same thing off Kijiji for \$500 with 2 batteries and a sling.</p>	ICII07

Table 9: Caregiver Needs with Relevant Quotes

Needs	Quote	
	[his IV] was hooked up to a machine and if the machine beeps it would freak us out because that would mean something was wrong. So I came home from work one day and that thing was beeping, and I asked how long it's been and "It's been like that all afternoon" and I remember thinking "Oh my god she said if this ever happens make sure you call right away." ... So then I phoned her and... she came and fixed it. It was something very mechanical...	ICII08
Medication Management	We were trying to get Temodar, which was the cancer drug. They were giving it to her at the hospital but they only had 2 days left and they are generally 3. So I started phoning around to pharmacies in [TOWN] and I got one, and he asked me if I had a P card... And I come home with 6 thousand dollars' worth of drugs. The chemo drug was 2 thousand plus a month, and every 4 weeks. Now if I was alone, and trying to get my wife settled... I would have struggled with the drugs. With setting up the drugs.	ICII03
	She was on anti-nausea drugs. One was administered with a needle. They taught me how to do that. They tried every 4 weeks upping certain anti-nausea drugs. [WIFE] was on Dilantin which was a steroid to bring down the swelling of the brain, and she was also on an anti seizure drug.	ICII03
	The only thing I didn't understand about the drugs is when they sent them home, ... is that to explain what every drug was for... And what might be the common name for something that has a medical Latin name.	ICII03
	Whenever she used to go for her treatment for her chemo treatment they put a device inside where they attached the IVs for the chemo... they showed us how to put the medication coming through a needle, and then putting it into the IV. So I had to learn that...	ICII05
	Then usually she had a routine with her pills. She had 3 different puffers to all take at different times... And that's pretty much most of the morning was all the pills. Then she started over again for lunch. She had another puffer to take and more pills. It was just an ongoing. Big containers and we kept writing them down "We took that one. We did that one..."	ICII06

Table 9: Caregiver Needs with Relevant Quotes

Needs		Quote	
		When we had to crush pills, it was recommended by the health professionals to go to a drug store and get one of these pill crushers and they're useless. Completely useless. So my personal support worker, recommended a mortar and pestle, for 10 bucks. And it's perfect. It's ideal.	ICII07
	Mobility	You're sort of always afraid of hurting the patient. In moving and repositioning. So in that regard, a book isn't necessarily the best thing... although they have diagrams there which are very helpful. They show you for example where bed sores are so you can keep an eye on them. Like the heels on her foot were starting to get red. So I never thought of the heels or the foot and under the knee... So, toileting, positioning in the bed, repositioning...	ICII01
		I had found him in the bathroom. It was the middle of the night, and he had fallen. And I went and I found.. I believe that he had hit his head against the ... So for 2 days he would say he has a headache...	ICII02
		She came home with more disability, with a cane all the time. She could still get up stairs. Both times after the operation she had physio...	ICII03
		She doesn't do the stairs much... she's more comfortable lying in the living room.	ICII04
		The CCAC visited her... and assessed them home was suitable and set-up alright with the proper safety	ICII06
	Nutrition	And we always get into the discussion about eating, hydration, are you going to start an IV. So you have to do all the education as to: the body is dynamic in the sense that it knows when to stop eating. So if you're trying to force this food now you're going to cause more problems; it could aspirate so now they have pneumonia. If we give hydration, if the body can't use it, it will go into the lungs or the legs, so you're actually causing harm more so and the body needs to shut down an arrhythmic way.	NFG member
		Before I was living there, she would go and have her own breakfast so she was capable for a while of going down to have breakfast, but obviously her appetite declined, very slowly over the period so it was very hard to encourage her to eat anything. She'd go down to breakfast and, where she used to have full breakfast, by the end she'd have a piece of toast and maybe her coffee and go back to her room and lie down... I think she was getting so weak she had Cachexia. She was very wasted away.	ICII01

Table 9: Caregiver Needs with Relevant Quotes

Needs		Quote	
		At the beginning they were able to feed him themselves because he was able to hold a cup and drink from it... But most of the time I was the one that measured the Ensure and water or the fluids.	ICII02
		In the second year we kept going with the chemo and we got to a point where we had it pretty well down what to eat prior to its start. She'd be on it for 5 days, eat the first night, and with all the anti-nausea pills she was taking, from the initial one after she got home after the first operation where she threw up 7 or 8 times a night, we were down to once or sometimes not even throwing up at all.	ICII03
		She'd try to eat as much as she could because I'm sure she was hungry, right? But she would gag. She tried to eat fruits or meat or something and she'd gag on it so whatever she needed, it was something that could go down easily.	ICII05
		I make sure that she has food on hand. It has to be pureed... And the only day that I feed her solely by myself is Sunday	ICII07
		We were trying to get him to drink Ensure and he just hated it. And he'd tell my children "hey guys your mom is selling Ensure" (laughs) I guess he didn't like it.	ICII08
	Pain	She's bringing a whole, totally different outlook of how her mother's going to die, because the children didn't die in a pleasant way so the fear is mother's going to die with pain and suffering.	NFG member
		And then pain management, especially for someone with dementia. How do you deal with pain management? What if they're just saying they're not in pain because they don't realize it? So I don't know what the answer is to that, you know what are the signs?	ICII01
		It's not that I wanted her to be unconscious. I just wanted her to be comfortable. It wasn't because I was trying to go to sleep. So that was the only issue. It was on pain management	ICII01
		She was on the morphine for the pain. And she had 3 different doses for that.	ICII05

Table 9: Caregiver Needs with Relevant Quotes

Needs		Quote	
Personal Hygiene & Elimination		Beginning when she had this terrible diarrhea, even with her Depends, you know, because she was so skinny, she was having accidents all over... At that point, she was still going to the toilet so it was very... That whole period was stressful	ICII01
		[Most challenging part] might be really changing him. With the diapers. Because the position was always a challenge for me because if I'm holding him and I'm alone, how do I at the same time put the diaper?	ICII02
		And then helped her take baths. Showers, we did showers. And then as it got worse I basically did everything that she couldn't really.	ICII03
		she'd go to the bathroom alone but we'd be in there with her. We'd help her to pull her pants down and put them back up because she couldn't really bend that much. But she was able to do her own urine and do her personal stuff herself. Her bath was... we'd have to help her but she'd wash herself and stuff like that.	ICII05
		when my mom wasn't bedridden. She was incontinent... And because she's a female I don't think it's proper for her son to change her diaper. I don't think that's reasonable. So I wouldn't, even though she's had an accident, I have to phone a female to come.	ICII07
Physical Symptoms and Comfort		... basically just symptom management: see how they're doing, making sure their bowels are moving, they're eating right, how their fatigue level is and how we can improve to maximize what they're doing in their daily routines.	NFG member
		... if the app was there I would have gone on the app and said "what things could I consider to make my family member more comfortable?" And then it would say "think about this or that? And these are possible sources"	ICII01
		The paralysis on her left side got worse. And we were able to get her a brace for her left leg which helped also. For her to get around. But that's basically it. Just the nausea in the last year or 2 years I think. The nausea.	ICII03